

Section 3

Moral perspectives

Section 3 – Moral perspectives

Overview

This section elaborates some of the perspectives and concerns that inform moral responses to genome editing. A starting point is the assumption that the object of modern science is the improvement of the human condition. The uncertainty of this outcome, the freedom of inquiry this entails, and the potential for scientific knowledge to support adverse as well as beneficial outcomes requires public trust in scientists and enjoins scientists in a corresponding responsibility towards society.

The question of whether intervening in the genome is of particular ethical significance is considered and the respects in which it differs from other interventions are discussed. The question of distinctive responsibilities falling on genome scientists and the relevance of how these have been addressed in the past (notably the Asilomar conference on recombinant DNA technology) is also discussed.

Transformative developments in bioscience are shown to exert pressure on established moral norms. Conservative responses arising from moral intuition, precaution, resistance to perceived technological determinism and the virtue of established order are distinguished. Attempts to constrain expanded uses of biotechnology in relation to discovered norms of biological form and functioning, and by how those uses conform with human rights are discussed, as are the advantages and challenges of using decision rules based on calculations of predicted gains or reductions in welfare. Questions of social, global and intergenerational justice are raised and the significance of how questions about the appropriate use of genome technologies are answered for the moral fabric of societies is noted.

The need to resolve questions of the governance of genome technologies at a public level in plural societies is noted and the importance of having an effective public sphere is suggested.

Introduction

- 3.1 This section will identify some of the key moral perspectives on genome editing, derived from our *Call for Evidence*, fact-finding meetings and research interviews, and our review of the relevant literature.⁷⁸ Because these are extracted empirically from expressed statements, the presentation of these positions does not represent a comprehensive ethical analysis. Nor does it follow a necessary sequence, since one perspective does not entail another: they represent alternative views, which may be found together in practice and reconciled, sometimes with difficulty, in public statements of opinion or policy. The purpose here is to uncover the grounds of moral reasoning that are currently in play in the discourse around genome editing and to distinguish different sources for *normative* claims about genome editing. Some of the arguments informed by these perspectives will be considered in subsequent sections, and particularly in the second part of our work programme.⁷⁹

Science as a moral enterprise

- 3.2 From the beginning of modern science, the pursuit of scientific knowledge was connected with the idea of moral purpose. In the *Advancement of Learning*, Francis Bacon famously counselled against the ‘greatest error of all’, being to mistake the ‘furthest end of knowledge’ for anything other than “the glory of the Creator and the relief of man’s estate”.⁸⁰ The Charter of the Royal Society, the UK’s national academy of science, likewise (or accordingly) refers to the President, Council and Fellows and their successors “whose studies are to be applied to further promoting

⁷⁸ See Appendix 1 (‘Method of Working’).

⁷⁹ Normative statements are of an evaluative or prescriptive kind; they are distinguished from statements that purport simply to describe or explain certain facts about the world, without expressing any disposition towards them. Norms that guide or constrain human behaviour may take different forms, for example in national laws or moral conventions. In the second part of our programme of work on genome editing, we will examine and develop arguments leading to normative claims about specific uses of genome editing that this ‘platform’ report has identified.

⁸⁰ Bacon, F (2000 [1605]) *The Oxford Francis Bacon, Vol. 4: the advancement of learning*, Kiernan M (Editor) (Oxford: Oxford University). By ‘the relief of man’s estate’ Bacon meant the alleviation of the sufferings afflicting mortal life.

by the authority of experiments the sciences of natural things and of useful arts, to the glory of God the Creator, and the advantage of the human race.”⁸¹ Whereas knowledge is seen as instrumental, it is an instrument with an inherent purpose; the pursuit of knowledge for other ends, such as vanity or self-enrichment, is seen as a moral failing.

- 3.3 In contemporary discourse on science, an emphasis on liberal and meritocratic concepts of scientific freedom and excellence is more likely to be found than statements of essential moral purpose: for example, the *Universal ethical code for scientists* places emphasis on the implicit contract between science and society, which makes scientific freedom conditional on doing no harm (rather than actually doing good).⁸² In reality the motivations and aims of scientists are likely to be more complex. Nevertheless, recent research by the Nuffield Council on Bioethics found that more working scientists put ‘making scientific discoveries for the benefit of society’ as their primary motivation for involvement in science than any other reason.⁸³ Irrespective of the intentions of scientists, it is hard to argue that the pursuit of science, particularly in the modern period, has not had a transformative benefit to ‘the advantage of the human race’. Nevertheless, the consequences of particular developments in knowledge are uncertain, and depend greatly on how they are put to use, wittingly or otherwise. As Bacon also noted, the mechanical arts are of ambiguous use, “and serve as well for the cure as for the hurt.”⁸⁴
- 3.4 The potential good of science and the implicit good will of scientists to avoid harm, in the context of an uncertain relationship between the scientific enterprise and its practical outcomes, is recognised in a common trope in social studies of science: the notional loan of trust or social ‘licence to practise’ given to scientists by society.⁸⁵ The relation between scientific inquiry and the broader public interest is also invoked to defend scientific inquiry against interference from commercial and political interests.⁸⁶ In return for these freedoms scientists are assumed to have an implicit responsibility towards society.⁸⁷ The degree of public trust and corresponding licence is, nevertheless, balanced between ambition and concern, and is sensitive to events and to narratives that celebrate the achievements of science, on the one hand, or draw attention to its failures, limitations and historical perversions, on the other.⁸⁸

Intervening in the genome

- 3.5 In our *Call for Evidence* we posed the question of whether or not there was anything special about the genome that might make intervening directly in the genome different from other ways of manipulating nature (e.g. selective breeding of plants or animals). Responses to this question mostly highlighted the ways in which intervening in the genome is different in virtue of its role in

⁸¹ See: <https://royalsociety.org/about-us/governance/charters/>. The formulation is found in the second charter of 1663 (and expands slightly on the reference to the ‘useful arts’ in the first charter of a year earlier).

⁸² This *Code* (2007), developed and promoted by the UK Government’s former Chief Scientific Advisor, Sir David King, is not binding, but is widely referenced. It is introduced by a quotation from Sir David: “Our social licence to operate as scientists needs to be founded on a continually renewed relationship of trust between scientists and society.” See: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/283157/universal-ethical-code-scientists.pdf.

⁸³ In a 2014 online survey of working scientists (n=790), 35% of respondents chose ‘making scientific discoveries for the benefit of society’ as the first response to the question ‘What motivates you in your work as a scientist?’, above ‘improving my knowledge and understanding’ (29%).

See: http://nuffieldbioethics.org/wp-content/uploads/The_culture_of_scientific_research_survey_analysis_for_web.pdf.

⁸⁴ Bacon F (1857) *Of the wisdom of the ancients*, available at: <http://www.bartleby.com/82/19.html>.

⁸⁵ Surveys and studies suggest that this is less about specific technologies or scientific advances but, rather, about the more general goals of science and its applications. See, for example, *Eurobarometer Responsible research and innovation, science and technology* (2013): http://ec.europa.eu/public_opinion/archives/ebs/ebs_401_en.pdf; for a US perspective, see: Nisbet M and Markowitz EM (2014) Understanding public opinion in debates over biomedical research: looking beyond political partisanship to focus on beliefs about science and society *PLoS ONE* 9: e88473. On ‘social licence to practise’, see Dixon-Woods M and Ashcroft RE (2008) Regulation and the social licence for medical research *Medicine, Health Care and Philosophy* 11(4): 381-91.

⁸⁶ See *Who owns science? The Manchester manifesto* (2009), available at: <http://www.isei.manchester.ac.uk/TheManchesterManifesto.pdf>.

⁸⁷ The *Universal ethical code for scientists* recognises the responsibility corresponding to the ‘social licence to practise’ as one of its three cardinal principles.

⁸⁸ On the negotiation between scientific and ethical orientations in the context of continuing research, see: Thompson C (2013) *Good science: the ethical choreography of stem cell research* (Cambridge, MA: MIT Press).

inheritance and the potential scale, seriousness and unpredictability of effects. However, there was little to suggest that the genome itself was an object of special reverence. We also posed a related question about whether any special responsibilities should fall on genome scientists, a suggestion that was, for the most part, robustly rejected: it was widely asserted that scientists had a responsibility to be open and candid about their work but these were felt to be responsibilities for *all* scientists, not peculiar to genome scientists, especially if the implication were that other scientists should be held to less exacting standards.

- 3.6 Intuitions about the significance of modification at a genomic level, as opposed to the modification of any other feature of an organism, are reflected in the various legal and regulatory provisions that apply to plants and animals (rules concerning GMOs in the environment and marketed for human consumption), and humans (gene therapy, assisted reproduction), as well as enhanced biosafety requirements for research. Concerns about the uncertain consequences of genome modification and the responsibilities of scientists to guard against them have long attended DNA research. They were the subject of a conference in 1975 that has become a point of reference for contemporary discussions about genome editing.

Box 3.1: The 1975 Asilomar Conference on Recombinant DNA

The conference on recombinant DNA held at the Asilomar Conference Grounds on the Monterey Peninsula, California, in February 1975 is often referred to as an important moment in the development of public responsibility within the science community.

The conference followed the raising of concerns about the potential safety hazards of (then) novel recombinant DNA technology, which allowed the combination of sections of DNA from different organisms and their insertion into a living host cell that was capable of propagating. The principal fear was that such experiments might give rise to new pathogens that could infect humans. At the instigation of researchers in the field, the US National Academies of Science (NAS) established a committee, which promptly called for a moratorium on recombinant DNA research pending an international conference to establish standards for research and regulation of biotechnologies.

The 1975 conference drew together the majority of the leading recombinant DNA researchers along with lawyers and medics, and its proceedings were placed in the public domain to encourage public discussion of research policy. As such it represents, for many, an important moment in wider public engagement with science policy in the recognition of the social importance of science and the social responsibility of scientists. (The December 2016 International Summit on Genome Editing, held in Washington, DC, under the auspices of the NAS, the UK's Royal Society and the Chinese Academy of Sciences was widely compared to the earlier Asilomar conference.)

The significance of the Asilomar conference is nevertheless disputed. Some consider it a lost opportunity or even a well-orchestrated subterfuge to allow research to progress with the minimum of external interference.⁸⁹ Its relevance to contemporary questions about genome editing has also been questioned, given that the scientific community concerned in the present case is large, diverse and globally diffused, that the issues are no longer about biosafety (about which reasonable scientific consensus is possible and which have, arguably, been settled) but rather about socially acceptable uses of the technology.⁹⁰

Responses to the challenge to established norms

- 3.7 In section 2 it was suggested that genome editing is a potentially transformative technology, not merely in an economic sense but also in a moral sense, in that it has the capacity both to produce new differences in the world and to provoke new ways of thinking about differences in the world. There is a need for normative judgements to respond to the world as it is presented in the current state of scientific understanding. The requirement to formulate public policy, which was discussed in section 2, therefore enjoins an effort to produce a working correspondence between scientific and normative discourses, so that they do not simply 'talk past' one another. There are numerous historical examples of where this correspondence has failed and had to be shored up or remade.⁹¹

⁸⁹ For a discussion of the relevance of the Asilomar comparison, see: Jasanoff S, Hurlbut JB and Saha K (2015) CRISPR democracy: gene editing and the need for inclusive deliberation *Issues in Science and Technology* 32(1), available at: <http://issues.org/32-1/crispr-democracy-gene-editing-and-the-need-for-inclusive-deliberation/>.

⁹⁰ Sarewitz D (2015) Science can't solve it *Nature* 522(7557): 413-4.

⁹¹ See Baylis F and Krahn T (2009) The trouble with embryos *Science Studies* 22(2): 31-54. The applicability of UK human embryology legislation to embryos created by somatic cell nuclear transfer ('cloning') was challenged in *R. v. Secretary of*

A notable feature of genome editing, also discussed in section 2, is the rapidity with which it has been adopted as an experimental technique and with which the production of research findings and the development of biotechnologies are progressing on several fronts. These new findings and new capacities are inevitably putting pressure on the normative judgements enshrined in moral and legal codes, by spelling out possibilities that lie beyond the boundaries established in such codes and projecting plausible pathways by which they might be reached. Put together, emerging tensions in the correspondence between scientific understanding and social and moral norms, and the difference in relative pace of development raise the stakes for attempts to find a coherent public response at an appropriate level.

Bioconservatism

- 3.8 One response to such developments may be characterised as moral conservatism or, as it has been called in this connection, ‘bioconservatism’.⁹² This is often framed through a morally invested opposition between the ‘natural’ and technological.⁹³ Broadly conservative responses can be a matter of taste, or linked with an (innate or conditioned) emotional reaction (what the US commentator, Leon Kass, memorably characterised as the ‘wisdom of repugnance’⁹⁴); they can, equally, embody a response to the perceived threat of technological determinism (in the sense of modern technologies shaping and regulating human capacities and actions).⁹⁵ Bioconservatism may arise from a reasonable concern about scientific hubris (for which a fictional apotheosis is Mary Shelley’s character, Victor Frankenstein⁹⁶), which is sceptical about the wisdom of human agents disrupting finely balanced systems that have reached their present state through lengthy evolutionary processes. For some it may have roots in their religious faith.⁹⁷ Whether this providence is thought to be divine or natural, human interference beyond a certain point may be thought to overreach the limited cognitive capacities of human agents and the limits of predictability for the systems in question.⁹⁸ Bioconservatism might refer to social, as well as natural, adaptation, appearing as a response to science moving too quickly for processes of public moral reflection to keep pace. Here, the idea is of a system of generalised judgements constituting a well-established system, instantiated in moral norms, cultural practices, regulatory codes and legal instruments, which has demonstrated its advantages and cultivated reliance on it among those it has served.

Normality, moral norms and rights

- 3.9 For many there are positive reasons to extend the use of new genomic technologies beyond the limits of existing practices, while remaining within some bounds of acceptability in order to avoid the putatively undesirable moral and social consequences of anomie. A way of grounding the

State for Health ex p. Quintavalle (on behalf of Pro-Life Alliance) [2003] UKHL 13 and later put beyond doubt by the Human Reproductive Cloning Act 2003; a similar concern related to human-animal hybrid or ‘admixed’ embryos (later provided for in the Human Fertilisation and Embryology Act 2008).

⁹² Although few authors self-identify as bioconservatives, the term is in currency in the bioethics literature. It transcends the political right and left, embracing those concerned about the effect of biotechnology on traditional values and ways of life and on social justice and equality.

⁹³ See evidence supporting the Nuffield Council’s 2015 work on *Ideas about naturalness in public and political debates about science, technology and medicine*, available at: see: <http://nuffieldbioethics.org/project/naturalness/the-findings/>.

⁹⁴ See: Kass LR (1998) *The wisdom of repugnance: why we should ban the cloning of humans* *Valparaiso University Law Review* 32(2): 679-705, first published as Kass, LR (1997) *The wisdom of repugnance* *The New Republic* (June 2, 1997): 17-26.

⁹⁵ See: Heidegger M (1977 [1954]) *The question concerning technology*, in *The question concerning technology and other essays*, Lovitt W (Translator) (New York and London: Garland Publishing), pp 3-35.

⁹⁶ Shelley, M (1992 [1818]) *Frankenstein; or, the modern Prometheus* (London: Penguin Books).

⁹⁷ This seems more marked in the case of individuals than in the official positions of faith organisations, and in the US than the UK. As part of our information gathering we consulted representatives from the Church of England, the office of the Chief Rabbi, from the Hindu Council UK, and the Sikh Missionary Society UK and the Muslim Council of Britain, as well as various Christian professional groups and NGOs. Despite differences of principle, which led them to place different conditions on the potential uses of genome editing, none was inherently opposed to genome editing in itself.

⁹⁸ Many of those who share conservative conclusions with regard to biotechnology may hold them for principled and socially progressive reasons, for example in view of their implications for human rights (see para. 3.9 below).

distinction between acceptable and unacceptable interventions is offered by the concept of what is *normal* in terms of the form or functioning for a particular class of biological entities. While nature contains many prodigies, the normal can serve to orientate moral action (for example, in terms of whether that action tends to support what is regarded as normal functioning or produce divergence from it). What counts as normal is therefore a legitimate question but often one that is highly contested with regard to the extent to which norms are related to natural states or socially constructed, particularly in relation to issues of disability, medical intervention and enhancement.⁹⁹ Disability justice and rights scholars have made a range of moral arguments against selective technologies, from individual rights based arguments such as the right to life of people with disabilities, to arguments for the social and emotional value (e.g. vulnerability to contingency) of biological difference, to the value to humankind of conserving disability cultures, and the importance of the visibility of disability in establishing social attitudes, behaviour, and structures.

- 3.10 The valorisation of natural order that led to natural law philosophies of the medieval period finds an echo in the post-Enlightenment concept of moral duty and, in the contemporary world, in the flourishing of the human rights discourse that followed the Second World War.¹⁰⁰ This locates a ground for moral claims in the inherent and inalienable dignity that people have simply in virtue of being human, and to which each has an equal entitlement for the same reason. Respect for human dignity, and the rights that flow from it, governs and delimits proper behaviour towards others (and through respect for one's own dignity and the interests of others, may also have something to say about treatment of other animals and the natural environment).¹⁰¹
- 3.11 The effect of asserting human rights is essentially to mark out and defend limits of tolerable behaviour: the concept of inherent dignity proposes to supply an objective ground for making distinctions between acceptable and unacceptable uses of technology, between normal and abnormal conditions, therapy and enhancement and other morally significant categories. Those who derive moral judgments from rights considerations often make the further claim that, without these concepts, such distinctions are vulnerable to erosion, creating a 'slippery slope' into practices that offend moral intuition.¹⁰²

Welfare and harm

- 3.12 Human rights are generally presented as grounds for claims against interference in the exercise of individual freedoms and, especially, against interference by public authorities. They ostensibly offer criteria to distinguish acceptable from unacceptable practices rather than offering a comparative evaluation of different possible courses of action. Such an evaluation may, however, be made on the basis of the consequences that different courses of action may be expected to produce. The theoretical position that the rightness or wrongness of an action is fixed by the consequences attributable to it is known as consequentialism. It offers the apparently simple rule that the action that should be selected is the one that produces the best consequences, all things considered. Utilitarianism is a variety of consequentialism that holds that consequences of action can be evaluated with reference to 'utility', which can be quantified, measured, aggregated, and subject to calculation to support a clear decision rule ('maximise utility') that will guide positive

⁹⁹ Canguilhem G (1991 [1966]) *The normal and the pathological* (New York: Zone Books). See also the response by the Center for Genetics and Society for arguments grounded in norms of medicine and reproduction. Assumptions made about quality of life of people affected by disabilities in debates about genome editing were highlighted in correspondence in *Nature* in 2015 (see: Shakespeare T (2015) Gene editing: heed disability views *Nature* **527**(7579): 446 and Wolbring G (2015) Gene editing: govern ability expectations *Nature* **527**(7579): 446).

¹⁰⁰ See: United Nations (1948) Universal declaration of human rights, available at: <http://www.un.org/en/universal-declaration-human-rights/>. See also: Glendon MA (2001) *A world made new: Eleanor Roosevelt and the Universal Declaration of Human Rights* (New York: Random House).

¹⁰¹ We acknowledge the substantial literature on animal rights although it was not explicitly presented to us in evidence during our *Call for Evidence*.

¹⁰² This position was put to us in evidence both from a Christian perspective and from a more secular position. For example, in the first fact finding meeting, by Robert Song, and also by respondents to the consultation, e.g. David A. Jones, from a Roman Catholic perspective, and Marcy Darnovsky, from a more secular position.

action.¹⁰³ Welfarism is a form of utilitarianism that identifies ‘utility’ with welfare.¹⁰⁴ This is useful for public policy because welfare is both broader than the private psychological states (such as pleasure and pain) and, though still personal to individuals, it is arguably subject to objective measurement.¹⁰⁵

- 3.13 The strength of consequentialism in debates about biotechnologies and biomedicine is that it focusses attention on the expected benefits as reasons to support scientific freedom and excellence. It also requires us to consider what we might be giving up if we rule out certain technologies because we believe they are ‘wrong’ *in principle*.¹⁰⁶ On the other hand, this kind of approach generally depends on promises and expectations about what might be possible, or about what benefits or harms might result from using biotechnologies when they are deployed in complex and unpredictable real-life conditions. As such it is inherently speculative.
- 3.14 Since the consequences of biotechnology and biomedical interventions for welfare are not always or necessarily positive, the welfare balance sheet has to account for the likelihood and significance of both benefits and harms that might result. In some cases discussed in this report, the possible ramifications of a given application of biotechnology – the possible mechanisms of action and their endpoints – are too many and too convoluted to comprehend. The introduction of irreducible uncertainty therefore substantially undermines the apparent simplicity of the decision rule.¹⁰⁷ Where the consequences that can be envisaged include highly undesirable and irreversible, or catastrophic outcomes, precautionary modes of governance may be recommended. Whether or not a ‘precautionary principle’ should be invoked in relation to any of the applications of genome editing requires more specific attention in the contexts of proposed use.¹⁰⁸

Social justice and just society

- 3.15 A particular concern that surfaced in our *Call for Evidence*, and that is found increasingly in relevant literature, is about the potential for the implementation of genome editing techniques in certain contexts (particularly biomedicine and human reproduction, but also agricultural and military applications) to have an impact on social, intergenerational or global justice (i.e. fair distribution of advantages or opportunities among different groups in a society, between one generation and the next or between nations, particularly the nations of the Global North and those of the Global South).¹⁰⁹ Such concerns require us to attend to the need to ensure that measures (such as the introduction of a new biotechnology) that affect welfare do so without discriminating unfairly among people.¹¹⁰ Although people may be equal in dignity and the enjoyment of rights, they are not equally situated with regard to the benefits and harms of biomedicine and

¹⁰³ The canonical definition of utility, given by Mill, says only that “actions are right in proportion as they tend to promote happiness, wrong as they tend to produce the reverse of happiness.” Mill JS (1971 [1863]) *Utilitarianism, Liberty and Representative Government* (London: Dent), at page 6.

¹⁰⁴ Sen A (1979) Utilitarianism and welfarism *Journal of Philosophy* 76(9): 463-89.

¹⁰⁵ There are some conceptual difficulties, in that interpersonal comparison of welfare is difficult (perhaps even impossible). All consequentialisms have difficulties with counting (how do we count those who are affected within any given time period, how do we cope with consequences into the future – including for future generations – and are we allowed to discount, etc.

¹⁰⁶ The comparative approach dispenses with the need for a distinction between what is acceptable and what is not; it requires only that judgements relate to which of the available options produces more welfare than the others.

¹⁰⁷ On the distinction between risk and uncertainty, see *Emerging Biotechnologies* (Chapter 3 ‘The threefold challenge of emerging biotechnologies’).

¹⁰⁸ The ‘precautionary principle’ and its cognates were invoked in a number of responses to our *Call for Evidence*. The use of the precautionary principle is highly contested and the principle itself is notoriously difficult to define, interpret and apply. This is discussed further in subsequent sections, in particular in relation to food (para.5.39) and the environment (para.6.30ff.)

¹⁰⁹ It is an acknowledged weakness of simple forms of consequentialism that they have little to say about how even or uneven the distribution of welfare should be among different people. (They may be interested in the experiences of people at all only insofar as they provide an index for the comparison between different possible states of affairs). Sen A (1979) Utilitarianism and welfarism *Journal of Philosophy* 76(9): 463-89; see also response to *Call for Evidence* by the Center for Genetics and Society.

¹¹⁰ A conception of justice as fairness was developed by John Rawls who, in *A theory of justice*, aimed “to generalize and carry to a higher order of abstraction the traditional theory of the social contract” as represented by Locke, Rousseau, and Kant.” Rawls J (1971) *A theory of justice* (Cambridge, MA: Belknap Press), at page 3; 10.

biotechnology. Certain people may be disproportionately affected, may find themselves (perhaps involuntarily) in circumstances that render them particularly vulnerable, or be excluded from access to decision making or to benefits that are available to others. As a result, they may experience unfair discrimination and systematic disadvantage. It is argued by many that dignity and rights discourse is, in fact, insufficient to ground socially just action and that a specifically social justice perspective is called for: they consider it to be essential to put in place means for tracking social justice outcomes over time, and social justice goals in regulation of genome editing technologies.

- 3.16 The locus of responsibility for producing and addressing injustice, and the morally appropriate means of doing so, are often matters of dispute. One focus of such disputes is the extent to which differences are intrinsic or socially constructed (i.e. repose on shared assumptions about the world that are not inherent or necessary but are taken for objective fact, and often embedded in procedures, institutions or ways of thinking) and is the subject of a substantial literature.¹¹¹ Furthermore, while there is no question that women, people of colour, and disabled people (for instance) experience injustice, harm, and indignity in all societies, the forms that this takes can be highly culturally, socially and historically specific (thus US, Brazilian and English racisms have many differences, for instance).
- 3.17 In many cases, public policy measures are thought to be justified to forestall negative personal and social consequences, such as exacerbating existing inequalities and further disadvantaging people who contingently occupy positions of vulnerability. However, such measures may be controversial, particularly where they impinge on the interests of others. So, for example, the claim that the use of technologies that have the effect of reducing the incidence of disability (say, Down's syndrome screening or preimplantation genetic diagnosis) expresses and compounds negative attitudes towards people with disabilities has been asserted, by some, as a reason to prohibit their use; others would see such a measure as an inadequately justified intrusion into private life and liberty. There is an obvious public interest in such technologies in that the public pays for much of the basic research through public taxation.¹¹² But that is not all: in many cases the nature of the technologies involves citizens much more intimately, especially in conjunction with genomic science, bioinformatics and precision medicine, where they and their bodies supply the data and raw materials (for example, baseline and index data, biological samples) for scientific discoveries and technological developments.
- 3.18 As well as forestalling or redressing unjust treatment of individuals, public policy measures both reflect and affect the kind of society in which they are implemented, including the relationship between public and private, how and to what extent different groups and members participate in social life, how different priorities, preferences and values are resolved or tolerated, how equal or unequal in power, status and wealth its members are, and how open or closed the society may be. The features of any society are complex, interdependent and dynamic, but public policy measures often imply and express consistent common values and may be articulated around a collective vision of the desirable future state that they are expected to contribute to bringing about. These, in turn, influence the behaviours, institutions and culture of the society, for example whether it is welcoming or hostile to difference in terms of ethnicity, belief, appearance or ability. How genome technologies are taken up in a society can both betoken and consolidate essential features of a society by posing important questions about what is for individuals or for society to determine, how common challenges are met and how goods are distributed.

Governance and democracy

- 3.19 An anxiety running through many responses to our *Call for Evidence* was the need for clear limits to distinguish morally acceptable from unacceptable uses of genome editing. It is this concern

¹¹¹ Many everyday phenomena (e.g. money) depend, for their social function, on conventional assumptions (e.g. about their worth). Others (e.g. 'economic migrants') may be subject to distinctive consideration or treatment based on beliefs that are shaped by social forces and embedded in language. See, in general, Berger PL and Luckmann T (1991 [1966]) *The social construction of reality* (London: Penguin).

¹¹² Mazzucato M (2013) *The entrepreneurial state: debunking public vs. private sector myths* (London: Anthem Press).

that, in many cases, animates the appeal for some robust or even objective standard of judgement. The elaboration of such a standard in practice, however, often runs up against disagreement. Many, if not all, societies include people who cleave to different standards of value and take different approaches to moral questions. There is often no orthodox and generally accepted source of ready-made moral judgements on the complex implications of scientific research. Nevertheless, on matters of public policy (where there is a public interest at stake, as we discussed in the previous section) it is usually necessary to arrive at a single conclusion on any given question (even if different people may have different reasons for accepting it). Indeed, while there may be profound and earnest disputes about theories of value, as there are between scientists about quantum physics or evolutionary theory, the content of moral judgements may show a reasonable degree of co-occurrence, as, for example, responses from different faith perspectives to our call for evidence showed.¹¹³ The problem arises in finding a way to resolve areas of inconsistency where it is more important to do so than to tolerate exceptions (or where exception itself is intolerable).

- 3.20 Arriving at a conclusion on matters of public ethics is, in a general sense, a kind of political activity. Democratic governance purports to offer a procedurally legitimate solution to controversial questions in morally plural societies.¹¹⁴ Yet, while they have the advantage of procedural legitimacy, all democratic procedures, to different extents, have a number of shortcomings: they are imperfect, slow, difficult and expensive (although for this reason they might answer the concerns of some moral conservatives that technology is moving ahead of society's ability to assimilate its implications to normative frameworks). Furthermore, although they are often bounded by the high level values of the society (e.g. conformity with established human rights), they effectively 'bracket out' second order ethical questions of substantive value and moral truth. Despite these shortcomings, democratic procedures nevertheless offer a plausible solution to, or way of coping with, the problem of the mutual adaptation of emerging biotechnologies and the normative frameworks within which they are deployed.¹¹⁵ Much of the evidence we received pointed to the importance of having an open, effective and inclusive public sphere in which questions about genome editing could be raised and discussed, in which different positions and arguments could encounter each other, and the importance of democratic governance.

Conclusion

- 3.21 If, as we concluded in section 2, genome editing is a potentially transformative technology, one that both displaces current ways of doing things and subtly changes the nature of what is done, and, furthermore, redraws the horizon of expectations about what may and should be done, it may thereby produce tension with existing systems of norms. At the very least, the different speeds at which biotechnology and governance develop may put them out of kilter. Such tensions make visible and call into question the underlying values on which moral and legal norms repose. In the submissions received in response to our *Call for Evidence*, a variety of different approaches to dealing with this tension can be identified. These include conservatism that seeks to restrain the ebullience of biotechnology within existing moral frameworks, and ways to accommodate novelty while seeking to limit it within bounds that are grounded in norms derived from nature or established by convention. Other approaches would direct the development of biotechnology according to principles of welfare maximisation, and control it in accordance with principles of justice that both protect those in positions of vulnerability and are intended to realise a coherent vision of moral society. To the extent that there is a public interest in genome editing and to the extent that this interest makes genome editing the object of public policy (or of other social or institutional norms) a practical approach will need to be found that acknowledges that people both

¹¹³ We received responses from the Church of England; the office of the Chief Rabbi; Hindu Council UK; the Sikh Missionary Society UK and the Muslim Council of Britain, as well as various Christian professional groups and NGOs.

¹¹⁴ For an appraisal of democratic procedures in bioethics, see: Parker M (2007) *Deliberative bioethics*, in Ashcroft RE, Dawson A, Draper H, and McMillan JR (Editors) *Principles of health care ethics* (Chichester: John Wiley & Sons), pp.185-91.

¹¹⁵ Presidential Commission for the Study of Bioethical Issues (2016) *Bioethics for every generation: deliberation and education in health, science, and technology*, available at: <http://bioethics.gov/node/5678>.

need a publicly coherent solution but may arrive at these questions with different thoughts about the nature of morality and different ways of valuing.