

**Human Nuclear Genome Editing:
A Paper by the National Council of
Churches of Singapore**

Executive Summary

The following contains an executive summary of our response from The National Council of Churches in Singapore (NCCS) to the Bioethics Advisory Committee (BAC) consultation paper “Ethical, Legal and Social Issues Arising from Human Nuclear Genome Editing”.¹

1. We first set out our understanding of Christian bioethics as part of our deliberation of Christian ethics, which in turn aims to paint a picture of the Christian moral vision. The Christian moral vision is concerned with human identity and the protection and flourishing of that identity in response to the Gospel of Jesus Christ.
2. We highlight, from a Christian standpoint, the danger of the philosophy driving much of our general bioethics and biotechnology toward a vision of human flourishing that consists solely in the elimination of suffering and the expansion of the boundaries of human choice.
3. We resonate with the BAC paper on its reasonable optimism regarding the promise of HNGE, and throw caution by drawing attention to the dangers of hype surrounding HNGE. In addition, we question what are the safeguards and limits that will enable us (as humanity) to say ‘enough’ in our pursuit of the further developments in HNGE.
4. We reflect on the kind of collective moral vision that will likely happen in a genetically-focused or a genetically-obsessed society, and question aspects of that society where genetic solutions are sought after at the expense of other more morally appropriate or proportionate techniques, or that pre-disease risk states are treated as if they were a disease in themselves.
5. While agreeing with the BAC paper’s recommendation that the ‘14-day rule’ remains (and not be extended to 28 days), we lay out our Christian position that the nascent human being in the form of an embryo is a human person even at the earliest stage. And since human persons are made in the image of God, they possess inviolable dignity and value from conception. As such, we are unable to support any means that involves the creation, destruction, and/or the eugenic selection of human embryos. With specific reference to heritable germline editing, we hold that the inevitable alteration of our human nature will have an inimical effect on our capacity to pursue the human good in terms of our flourishing.
6. We consider the impact on society, and state our concern that the advent of widespread genetic screening and therapies will lead to a society that sees genetic diseases as a condition to be avoided at all costs, even life itself. To that concern, the church declares unambiguously that the presence of genetically compromised persons in society is good, simply because they are there and they are the gift of a loving God who welcomes us all. If this last statement is affirmed, steps must be taken to ensure that the development of HNGE in medical care and research does not come with an increase in discrimination or stigmatisation (e.g., only a certain

¹ Bioethics Advisory Committee, *Ethical, Legal and Social Issues Arising from Human Nuclear Genome Editing* (Singapore: 2024), <https://www.bioethics-singapore.gov.sg/>

affluent segment of society can afford it) that results in an economic distributive injustice.

7. We recommend that yardsticks be clearly stated in order that we can draw the line and distinguish between therapy and enhancement.

In conclusion, we affirm our response that the Church is neither a pure advocate nor opponent of technology or advancement. Instead, it is in being captured by our moral vision that grants us the dignity, freedom, and responsibility to choose what is right and sound, and not only what is expedient or popular. We find our bearings within that moral vision in the givens of human life, the dignity of the human person, and our care for the common good, not just the individual. The key question that is addressed in the public bioethics of gene editing is the question about what it means to be human: what vision of humanity lives at the heart of our public reasoning? To that question we are appreciative of BAC's stance that a human project as large and momentous as HNGE must continue to consider the vast wealth of human wisdom: social, political, scientific, philosophical, and, critically, moral and religious capital. In the process, we must hope and pray that we do not end up trading in wisdom for knowledge.

Introduction

In June 2023, the Bioethics Advisory Committee (BAC) published their consultation paper “Ethical, Legal and Social Issues Arising from Human Nuclear Genome Editing”.² The National Council of Churches in Singapore (NCCS) has gratefully accepted an invitation from the BAC to respond to the paper.

The NCCS commends the BAC for a wide-ranging and cogitative discussion surrounding the vast hinterland of issues associated with human nuclear genome editing (HNGE). Given the gravity of the subject, the considerable expertise of the review group, comprehensive coverage of the issues, and careful examination are all praiseworthy features of the consultation paper.

The BAC paper covers ethical, legal and social issues. We thank the BAC for the invitation to comment on the consultation paper. As Albert Jonsen recognises, the discipline of bioethics has been enhanced by the salutary contributions of moral theology.³ Certainly, the same is true for the NCCS and the BAC. We are grateful for the invitation to offer this paper, and what follows is not an expository critique of the BAC’s valuable consultation paper but part of extending the excellent partnership that Christian moral reflection offers to the BAC and society as we reason together on the vision of human identity and the laws and public policies that exist for the protection and flourishing of humanity.

Moral Vision and Christian Bioethics

Christian bioethics is part of Christian ethics and, as such, springs forth from the response of the Church to the Gospel of Jesus Christ, a response which takes the form of loving worship and faithful witness. Christian ethics provides not one abstract rule after another but an education in a “large-scale interpretive framework with which to discern the meaning of things in relation to God.”⁴ Christian bioethics aims to situate developments in life in their proper relation and, therefore, to their right status.

The temptation to reduce bioethical discussions to specific technologies or concrete case studies arises from a view of ethics as a tool to resolve or illuminate dilemmas, cases of conscience or moral quandaries. Yet, as has been cogently argued by theologians such as Stanley Hauerwas, focus on moral quandaries neglects how quandaries are construed. What appears to one as a moral quandary may, in fact, be the result of one’s moral vision. As Hauerwas rightly observes, “‘Situations’ are not ‘out there’ waiting to be seen but are created by the kind of people we are.”⁵

² Bioethics Advisory Committee, *Ethical, Legal and Social Issues Arising from Human Nuclear Genome Editing* (Singapore: 2024), <https://www.bioethics-singapore.gov.sg/>

³ Albert R. Jonsen, *The Birth of Bioethics* (Oxford: Oxford University Press, 1998)

⁴ John F. Kilner, ed., *Why the Church Needs Bioethics* (Grand Rapids, MI: Zondervan, 2011), 175.

⁵ Stanley Hauerwas, *The Peaceable Kingdom: A Primer in Christian Ethics* (London: SCM, 1984), 116.

For this reason, one of the priorities of Christian ethics, bioethics included, is to distance itself from purely issue-centred bioethics. Christian bioethics has a goal of communal shaping and discernment of the Church. This ethical discernment is a corporate activity, not just the sole preserve of theologians or ethicists. It cannot evade broader questions of justice, such as costs, data privacy, proper governance, or resource allocation.

Most of all, Christian bioethics cannot narrow its focus simply to biomedical research, practice, and regulation. It extends its gaze wider to the social and ecological dimensions of biomedical research and practice and to the cultural commitments which they embody. This is even more acute than in questions raised by the spectre of HNGE in conjunction with other developments such as Big Data and Artificial Intelligence.⁶ The rapid advances and technological developments in these areas make this a frontier science. This underlies the unsuitability of an issue-by-issue response, not least because there is no conceivable situation where our capacity for moral reflection can keep pace with new technologies as they appear on the horizon.

Reflection is needed on the underlying frameworks of thought and practice that have helped create these technologies and will continue to shape their future development—a failure to consider these limits bioethics to attend only to presenting issues of each new technology. But to do so is to admit of a failure to understand any such technology meaningfully. Without an appreciation of these developments' underlying cultural and ideological currents, bioethics is doomed to be endlessly reactive, only capable of responding if and when the next moral crisis over a technology erupts. In recent memory, one landmark case in genetic technologies is that He Jiankui, a genome-editing researcher who claimed to have impregnated a woman with embryos edited to turn off the genetic pathway HIV uses to infect cells. Reporting on the international outrage, David Cryanoski and Heidi Ledford nonetheless note that “many in the field thought it was inevitable that someone would use genome-editing tools to make changes to human embryos for implantation”.⁷ In the face of the seemingly unstoppable juggernaut of technology, and perhaps the immovable temptation to deploy these technologies, we need sustained reflection which attends to the broader historical and cultural movements that animate our moral sense of these technologies.

Christian bioethics is committed to just such reflection, not least because it is interested in going beyond solving dilemmas to perhaps more fundamentally articulating the moral vision that illuminates and reveals whether these dilemmas genuinely exist or are conditioned by the way we have come to see things.

The Baconian Project

An example of this is Gerald McKenny's *To Relieve the Human Condition*. McKenny traces the modern bioethics project to what he calls “the Baconian project”, named after

⁶ See “NCCS Response to Big Data and Artificial Intelligence in Human Biomedical Research”, 2023.

⁷ David Cryanoski and Heidi Ledford, “International outcry over genome-edited baby claim,” *Nature* 563 (November 2018), 608.

the British philosopher Francis Bacon.⁸ The project centres on two imperatives: eliminating suffering and expanding the boundaries of human choice. This had its roots in the convergence of practical compassion to secure the well-being of one's neighbour with a new natural science that disposed of a classical teleological account of nature in favour of a mechanistic philosophy of efficient causes. This rendered nature suitable for technological and instrumental control, which could be manipulated at will to benefit human beings. This, together with subsequent developments in utilitarianism, reduced the determination of human good to a calculus of pleasure and pain. With this grew an increasing doubt about finding any meaning in suffering. Suffering, therefore, became something to be avoided or eliminated wherever possible. Contemporary ideals of individual autonomy allied with developments in technology that dramatically increased the scope of our medical interventions have only fuelled the emphasis on self-determination in relation to one's body. As McKenny puts it, "the commitment to realise one's uniqueness leads to cultural expectations that medicine should eliminate whatever anyone might consider to be a burden of finitude or to provide whatever anyone might require for one's natural fulfilment."⁹ The body, in other words, is subordinated to the autonomous will with the expectation of its indefinite plasticity. The human good has been reduced in the modern moral imagination to something essentially biological.

McKenny's erudite account of the Baconian Project and others like it help us see through the fog of technological quandaries in the present.¹⁰ The upshot is that we can more clearly see the existential dimension of modern biotechnology. By showing how existence is conceived as a matter of escaping the clutches of blind fate by means of technology, McKenny helps us to see how modern bioethics might be complicit with absolutist commitments to personal liberty, technological control, and relief from actual and potential suffering. Any alternative view which asks not how biotechnology can be subordinated to the desire to transcend the fragility of human existence but instead how sickness and health might be integrated into a morally valuable life that has come to terms with finitude and mortality is, as a matter of course, dismissed. Insofar as mainstream bioethics is unavoidably and unwittingly complicit in this project of personal autonomy, technological mastery, and relief from suffering, it is unlikely to be able to sustain any substantial critique of it. This reductive vision of the body is what Pope Francis calls the technocratic paradigm: an endless search for control over nature.¹¹

In such a mode, bioethics might even arise from a similar desire to master contingency and relieve the human condition. In the face of chance and fate, ethics becomes a form of justification, a way of elevating ourselves above the auspices of pure chance and assuaging our conscience of having done our very best to do what is right in our own eyes. Karl Barth's observation that "what the serpent has in mind is the establishment of

⁸ Gerald McKenny, *To Relieve the Human Condition: Bioethics, Technology and the Body* (Albany, NY: State University of New York Press, 1997). What follows is a *precis* of his argument in 17-24.

⁹ *Ibid*, 20.

¹⁰ Another salient example of this kind of broader analysis is Charles Taylor's *Sources of the Self: The Making of Modern Identity* (Cambridge: Cambridge University Press, 1989).

¹¹ Pope Francis, *Laudato Si*, especially §106-114.

ethics” is a salubrious reminder that a bioethics unaware of its complicity in such projects stands in danger of the idolatry of self-justification.¹²

It goes without saying that Christians do not uncritically reject all individual technologies that attempt to relieve suffering or elevate the human condition above the level of fatalism. Relieving suffering and exercising choice are not bad goals. On the contrary, Christians accept that it is precisely because they are good that it is difficult to recognise when they might be distorted or alloyed with ideals which are morally problematic.¹³ The aim of restoring health is proper to the right exercise of biotechnology, but it is another thing altogether to reform it.

The fact is that Christian bioethics can offer to the world much more than our caution. We can and do confidently speak of the distinctive witness of the Church that unmask idols, deflates unreasonable expectations, liberates us to ask how much medical and technological progress is suited to the flourishing of humanity, fears no irrelevance more than irrelevance to God, and also confidently asserts God’s desire for the healing of the nations.¹⁴

Human Nuclear Genome Editing

The BAC consultation paper is laudable for its clear-eyed articulation of issues related to HGNE. The paper does not gloss over the severity of concerns raised by the development and deployment of HNGE, such as mosaicism, off-target effects and other undesirable consequences. It rightly raises questions over safety and long-term effects, particularly because the technology is still considered in its nascent phase. Other issues addressed include the procurement and use of human embryos and oocytes for research, the allocation of resources and access to these new technologies, and questions of governance and framework.

The paper does not only cover bioethical points of concern. Fittingly, the paper highlights many promising ways that HNGE might be applied in research and clinical applications to treat diseases. Promising applications of HNGE discussed in the paper include cancer research to understand tumorigenesis, developing effective treatment modalities for targeting tumour cells, growth in understanding genetic mutations that lead to neurodegenerative diseases, and genetic enhancement for conferring resistance to diseases.¹⁵

¹² Karl Barth, *Church Dogmatics*, IV/1 (Edinburgh: T&T Clark, 1956), 448. An observation that augments our application of Barth’s axiom is that secular bioethics around the world has integrated much of what was once morally and scientifically controversial into medical practice: abortion, surrogacy, organ transplantation, gender reassignment surgery, plastic surgery and so on.

¹³ Robert Song, *Human Genetics: Fabricating the Future* (Cleveland, OH: Pilgrim Press, 2002), 118.

¹⁴ Robert Song, “Christian Bioethics and the Church’s Political Worship”, *Christian Bioethics* 11:3 (2006), 347.

¹⁵ For this and other benefits addressed, see Bioethics Advisory Committee, *Human Nuclear Genome Editing*, 45-57.

However, as mentioned earlier, if Christian bioethics is to meaningfully contribute to the discussion of HNGE, it must raise questions about the broader currents situating the development of genetic biotechnologies.

HNGE: Hope or Hype?

In 1997, Craig Venter and Daniel Cohen, two of the world's leading genetic scientists at the time, published an article declaring the 21st century "the century of biology". According to Venter and Cohen's exuberant description,

for the first time, we will have a complete description of life at the most fundamental level of the genetic code. This map will describe for us the exact content and structure, not only of each and every gene associated with a species but also the precoded information... that controls when a particular gene is turned 'on' or 'off', leading to a biological effect. In humans... this means we will know exactly what genetic predisposition makes a person susceptible, say to prostate cancer or Alzheimer's disease. We will also know how to manipulate a gene to produce blue eyes or dark skin.¹⁶

Yet, the same year this article was republished, Elizabeth Pennisi also cooled Venter and Cohen's seemingly untrammelled optimism by explaining that "molecular biologists may have sequenced the human genome, but it's going to take molecular cryptographers to crack its complex code." As she goes on to explain, genes cannot by themselves provide full explanation for what makes cows cows and corn corn, as "the same genes have turned up in organisms as different as, say, mice and jellyfish." In fact, Pennisi suggests that it is not the genes *per se* but the genome's control of each gene's activity that matters the most.¹⁷ To say that humans share 98% of our genes with chimpanzees, most of our genes with mice, or even 50% of our genes with flowers might imply that we are genetically related to plants, close to mice, and practically siblings with primates. Yet the truth is, as Celia Deane-Drummond states, the same gene can code very different physical characteristics or phenotypes.¹⁸

It must be said that the BAC paper does not hit the same optimistic heights as Venter and Cohen. The paper relies on established principles of bioethics, such as solidarity, sustainability, proportionality, and justice, to anchor and temper the expectations of HNGE in research and clinical applications. The paper repeatedly asserts the need for further studies on HNGE in different contexts to be conducted to understand its consequences fully.

The truth is that, as Joshua Hordern has perceptively pointed out, HNGE emerges amidst an ethos of promise, and there is a real cost to lives because human finitude

¹⁶ The 1997 article was republished later in Craig Venter and Daniel Cohen, "The Century of Biology", *New Perspectives Quarterly* 21 (2004): 73.

¹⁷ Elizabeth Pennisi, "Searching for the Genome's Second Code", *Science* 306: 5696 (2004): 632.

¹⁸ Celia Deane-Drummond, *Genetics and Christian Ethics* (Cambridge: Cambridge University Press, 2006), 125.

means that promises always involve uncertainty.¹⁹ There is always the danger that the scientific community and society might lose themselves in the idea and promise of precision medicine and for that promise to become distorted into hype. Lurking nearby is the related danger of immodest promises.

Hordern draws our attention to how hyped-up promises shape people's lives and the procedures they might consent to in response to the hope or fear engendered by the promise of HGNE. For example, he cites how patients being excluded from certain trials led to immense disappointment or pressure to participate in future trials. In his reading, there is a need for more qualitative research on the perception of risk and the future. Furthermore, he explains that the patient's journey can be disrupted as compassionate companionship suffers in the face of rising complexity. As research or clinical pathways cease or fragment, the patient nonetheless journeys through life towards suffering, disability, and even death.²⁰

For researchers, Hordern asks if the promise of precision in fields like HNGE might so captivate researchers so as to unduly pressure them to ensure that trials don't fail. In other words, there is a felt requirement to make history right. For policymakers and governments, Hordern posits that the promise of precision medicine is that it seems to bypass intractable problems in societal health and that it seems to be at the cost of further attention to other important aspects of treatment, such as patient behaviour and environmental outcomes. Hordern's description of the costs of the hype and promise of HGNE matches Theresa Feiler's description of genomic medicine and the way the scientific community thinks of it. In Feiler's view, the promise of genomic medicine can result in an environment where "critique is seen as suspicious: anti-progressive and Luddite" because the inward discovery of humanity was said to culminate in the genome.²¹ In such an environment, diverting resources from genomic research can be controversial.

Our responsibility is to complement the BAC consultation paper by drawing attention to the dangers of hype surrounding HNGE. The question of overhype or fantastic promises about HNGE raises a cluster of related issues. One such issue, already hinted at earlier, is our gap in knowledge of both intended and unintended consequences. Somatic gene therapy, for example, raises the possibility of mosaicism or insertional mutagenesis, which can result in cancer. We simply have no way of knowing the long-term outcomes of gene therapy. A study published in 2010 showed that four out of nine patients who received gene therapy for SCID-X1, a congenital immunodeficiency, developed acute leukaemia. Although the therapy successfully corrected the immune dysfunction, the

¹⁹ Swiss Academy of Medical Sciences, *Summary Report of the FEAM Conference 2018 on Precision Medicine and Personalized Health* (Geneva: 2018), 23.

²⁰ Joshua Hordern, "Ethical Imperatives for Personalised Medicine: A Costly Promise?" (Presentation, FEAM Conference 2018 on Precision Medicine and Personalized Health, Geneva, September 28 2018).

²¹ Theresa Feiler, "The Ontology of Personhood: Distinguishing Sober from Enthusiastic Personalised Medicine", *Studies in Christian Ethics* 32 No. 2 (2019): 257.

treatment is associated with a significant risk of acute leukaemia. The follow-up period was a median of nine years.²²

The most famous example of somatic gene therapy producing lethal side effects was the case of Jesse Gelsinger, who died in 1999 after a somatic gene therapy trial for ornithine transcarbamylase deficiency. A healthy volunteer who had suffered only relatively mild effects of the disease, Jesse died in phase I of the trials, four days after receiving his first injection of the trial.²³ Other examples include two boys in another SCID trial who developed leukaemia and a haemophilia trial that was halted because seven patients developed signs of mild toxicity.²⁴

Our mention of these examples is not to cast aspersions on the genuine promise of HNGE. Gene therapy is complex, and reductionist conclusions fail to consider poorly understood or unexpected factors such as immune response, environmental effects, pleiotropy or variable expressivity, and reduced or incomplete penetrance. Researchers must be prepared to admit that a veil of ignorance still hangs over our genetic knowledge. Gene-editing targeting specific somatic diseases is, in some ways, a frontier medicine, and building on prior research is only sometimes possible. Even with research, as is the case for the SCID-X1 study, it could take up to nine years to confidently conclude both gene therapy's success and dangers. When a deleterious mutation is edited out, the consequences of the edit may not be fully known, especially in cases where mutations have multiple implications for an organism.

The incompleteness and opacity of our knowledge challenge the principle of informed consent. It would be difficult to explain or get a firmer grasp on the perception of risk and reward. Regarding the hype, there might be a tendency to over-promise or overly optimistic in benefit projections, especially when researchers seek consent. We would be cautious of the potential of HNGE generating a mystique of unrealisable promises and undeliverable expectations about precise genetic treatments. Tim Maughan explains that biomedical research is “suffused with optimism” regarding the ability to “deliver massive improvements in clinical outcomes, built on the remarkable benefits of novel therapeutics in disorders driven by a single genetic alteration.”²⁵ This can lead to destructive risks in research funding where grants are allocated to areas of apparent (but overhyped) success to the detriment of other important areas. It also risks exaggerated expectations distorting clinical commissioning. Perhaps most concerning is the risk Maughan outlines of abandonment of proven ways of treatment for a highly risky, unrestricted use of novel therapies in the hope of a breakthrough.²⁶ The risk of hype affecting clinical consultations, resource allocation, and funding prioritisation is real. We will need sober-minded researchers and policymakers who can communicate when one

²² Salima Hacein *et al*, “Efficacy of gene therapy for X-linked severe combined immunodeficiency,” *The New England Journal of Medicine*, 363 No. 4 (2010): 355-64.

²³ Adam Bostanci, “Blood Test Flags Agent in Death of Penn Subject,” *Science* 295 No. 5555 (2002): 604.

²⁴ As mentioned in Celia Deane-Drummond, *Genetics*, 129.

²⁵ Tim Maughan, “The Promise and the Hype of ‘Personalised Medicine’,” *The New Bioethics* 23 No. 1 (2017): 16.

²⁶ *Ibid.*, 17-19.

might reasonably expect wide-scale genetic therapies. Indeed, ensuring that HNGE and technologies like CRISPR “do not become touted as a panacea for all genetic illness is crucial for proper application and dissemination of the technology.”²⁷

We would raise one final caution on the promise of HNGE. As the BAC paper rightly emphasises, any proposed applications or research must first have evidence of its safety and efficacy. This is right; if any treatments were unsafe or ineffective, they would be morally impermissible on even the most permissive analysis. Given the examples above, this raises the issue how researchers, doctors, and scientists might consider forms of gene editing, the long-term effects of which are not, in principle, determinable or reasonably predictable. We would counsel policymakers to reserve the freedom to say perhaps that some forms of editing – such as heritable germ-line editing – are off-limits. In any case, Bill McKibben’s *Enough* helps us to ask ourselves a question: can humanity learn to exercise our ability to say *enough* when it comes to new technologies, or are we destined to lust for more and higher capacities that cloud our human capacity to say no?²⁸

A sober approach to HNGE will, without doubt, prize the role that genomics can play in the medical care and cure of disease, but in a way that situates it properly as one of a suite of treatment options. Christians take seriously the reality of suffering and certainly treat death as the last enemy. But we do not see suffering and death as something to be denied, in the final place, at all costs; neither do we view death as a traumatic failure of technology. Against the backdrop of choice, consent and control as noble but ultimately futile means of eradicating death, Christianity offers us the theological virtue of hope, which allows us to trust in God’s providence, knowing that his plan is far superior to our fears and efforts to overcome them.²⁹ A sobered optimism – hope, not hype – in HNGE faces up to rather than postpones engagement with human limits and frailty.

The Danger of Overmedicalisation in An Overtly Genetically Focused Society

Christian bioethics is concerned with moral vision, character, and agency. That is to say, it is not simply issue-based dilemmas we are concerned about, but the kind of moral vision that society seeks to instantiate and by which it views reality. This, as has been mentioned, is important because our moral vision frames whether something occurs to us as a problem or not. One example of this is seen in genetic screening. The BAC paper refers to HNGE in research in terms of helping us to understand the pathology and aetiology of diseases. One such example is in the area of prenatal screening. Celia Deane-Drummond thinks that once a pregnant woman has accepted the invitation to be screened, she has ventured on a path that almost inexorably leads to medical intervention. Since the most likely form of treatment following the discovery of a genetic

²⁷ Arther Caplan *et al*, “No Time to Waste – The Ethical Challenges Created by CRISPR,” *EMBO Reports* Vol. 16 No. 11 (2015): 1426.

²⁸ Bill McKibben, *Enough: Staying Human in an Engineered Age* (New York: Henry Holt Co., 2003)

²⁹ Joseph Tham, “Resisting the Temptation of Perfection”, *The National Catholic Bioethics Quarterly* 17.1 (2017): 61.

disease is likely termination, the number of live births judges the effectiveness of genetic screening. “That is to say, the number of terminations is considered to be the measure of the effectiveness of genetic services.”³⁰ Here, the dark shadow of negative eugenics casts a pall on genetic screening.

One could argue that the dark shadow of negative eugenics would be dispelled if genetic screening led to therapeutic uses of HNGE. However, it is worth pausing to ask what would happen if mass screening and treatment were *di rigueur*. In effect, we would all be patients, all with a genetic profile that lists our propensity for disease. What kind of life would we lead if we discovered all the diseases that could or are likely to affect us in the future? Genetic prediction leads to the expectation that we would manage the present by adjusting our lives according to these genetic parameters. Christiane Woopen predicts that the future will be where “more and more tests are done, more and more diseases feared, the worries about health take on a growing space in people’s consciousness, in their responsibility and lifestyle.”³¹ Likewise, Giovanni Maio thinks that

the more we know about predispositions through genetic testing, the more our health and our diseases will seem to be results, products of our own actions, indeed products of our own will... In return, the person who is ill will be confronted with the underlying question of why they became ill and, if not genetically advised, whether they could not have prevented the outbreak of the disease by taking a predictive genetic test.³²

This should prompt reflection on the kind of collective moral vision happening in a genetically focused society. Would a genetically focused society be in danger of tending towards dehumanisation? Would a genetically focused society overlook other ways of addressing issues? One possible answer to this could be to refer back to He Jiankui’s attempt at clinical gene editing for the sake of genetic enhancement. His stated goal was to make babies more resistant to HIV infection because so many children in China are affected by the virus and face discrimination.³³ However, HIV infection can be avoided altogether by non-genetic means. Discrimination is also a social problem rather than a medical one. His stated motivations for his maverick experiment seem particularly ill-fitting and serve as a reminder that a genetically focused society may reach for genetic solutions at the expense of other more morally appropriate or proportionate techniques.

What we mean by proportionality and HNGE can be illustrated with reference to the Christian just war tradition. Oliver O’Donovan reminds us that proportion has to do with the “rational form which such an act assumes”, that is to say, with the shape of a successful act of judgment. On the one hand, an act of judgment is reflexive. It looks

³⁰ Celia Deane-Drummond, *Genetics*, 90.

³¹ Christiane Woopen, “Individualisierte Medizin als zukunftsweisendes Leitbild”, as quoted by Feiler in “The Ontology of Personhood,” 259.

³² Giovanni Maio, “Chancen und Grenzen der personalisierten Medizin – eine ethische Betrachtung”, as quoted by Sebastian Wäscher, “‘Personalised Medicine’ in Oncology: Physicians’ Perspectives on Contributions to and Challenges for Clinical Practice”, in Jochen Vollmann, et al, eds., *The Ethics of Personalised Medicine: Critical Perspectives* (Abingdon: Routledge, 2015).

³³ Suzanne Sataline and Ian Sample, “Scientist in China defends human embryo gene editing”, *Guardian* Nov 28 2018.

backwards, pronouncing a judgment on a current state of affairs brought about by previous acts or failures to act. This requires a “truthful description of what the wrong that is done.” On the other hand, since an act of judgment also looks forward, it must be proportionate to the state of affairs which it attempts to bring about. What is undertaken must correspond to what is purposed, and what is purposed must correspond to a reasonable complaint.³⁴ As Hugo Grotius says: “The danger must be immediate... those who accept fear of any sort as a justification for preemptive slaughter are themselves greatly deceived and deceive others.”³⁵

The Christian just war teaching on proportionality might be meaningfully applied to preventative measures and the treatment of risk. Paul Scherz’s caution against the increasing encroachment of healthcare in terms of mitigating and reducing risk comes to mind. For Scherz, seeing health in terms of reducing the risk of disease quickly slides into defining the risk itself as a disease. Interventions to reduce risk lead to increased risks, uncertainty, excessive medical expense, and iatrogenic effects.³⁶ This also endangers our moral vision by reinforcing an unhealthy focus on efficiency and autonomy. Moreover, because there is an unlimited scope for risk reduction, the focus tends overtly to individual changes rather than social changes, undermining care for the common good and solidarity. Endless individual medications or interventions replace social changes in light of risk calculations based on individual genetic sequences.³⁷

Furthermore, in *Risk Society*, Ulrich Beck argues that

gene technology puts humankind in an almost godlike position, in which it is able to create new materials and living creatures and revolutionise the biological and cultural foundations of the family. This generalisation of the principle of design and constructability... exponentiates the risks and politicises the places, conditions and means of their origin and interpretation.³⁸

In other words, the possibility of genetic intervention heightens rather than reduces anxiety about the future. A risk-averse society attempts to tame chance by making interventions based on probabilistic guesses derived from genetic services – screening, counselling, prenatal diagnosis, etc.

In our view, one of the dangers of the promises of HNGE is the slide towards treatment of pre-disease risk states as if it were a disease, thus uncritically sanctioning the genetic equivalent of a pre-emptive strike. Biotechnological triumph, in this construal, can

³⁴ Oliver O’Donovan, *The Just War Revisited* (Cambridge: Cambridge University Press, 2003), 48; 52.

³⁵ Grotius, *De iure*, 2.1.5.

³⁶ Paul Scherz, “Risk, Health, and Physical Enhancement: The Dangers of Health Care as Risk Reduction for Christian Bioethics,” *Christian Bioethics: Non-Ecumenical Studies in Medical Morality* Vol 26. No. 2 (2020), 146.

³⁷ Consider, for example, Nicanor Austriaco’s argument to make people “healthier than healthy”, as he argues in favour of a genetic therapy to eliminate the function of the *PCSK9* gene, resulting in greatly reduced blood LDL levels. Austriaco seems to suggest that there is no straightforward response to how low LDL levels should be, opening up the endless pursuit of lower numbers beyond even traditional LDL thresholds indicative of health. Nicanor Austriaco, “Healthier than Healthy: The Moral Case for Therapeutic Enhancement”, *The National Catholic Bioethics Quarterly* 17 No. 1 (2017): 43-9.

³⁸ Ulrich Beck, *Risk Society: Towards a New Modernity* (London: Sage, 1992), 51-2.

become an end in itself, rather than traditional forms of healthcare that see medical interventions for the reasonable and feasible goal of restoring a patient's health. A forward-looking proportion must proportion an action in relation to its end. Our concern is that a failure to discuss these ends will lead to a failure in proportionate discriminatory acts of judgment. This is a kind of deficiency of moral vision and judgment that the Church should be on guard against.

HNGE and the Human Future

The question of moral vision leads us to reflect deeply on the bioethics of future possible applications of HNGE to gene editing in embryos, germline editing, and even heritable gene editing for clinical applications. As the BAC paper observes, heritable gene editing is currently under a worldwide moratorium. Yet human ingenuity and technological progress are not to be dismissed. The discovery of CRISPR made targeted gene editing possible in ways researchers and scientists could not imagine before. Even if the technology or the will to heritable gene editing is further afield, it behoves us to consider what bioethics limits, if any, exist to aid our reflection. There is a feedback loop between our ideals of autonomy and the technologies we craft to pursue those ideals. If we are beholden to something like the Baconian Project, then not only will our norms guide our innovations – but our subsequent innovations will also shape or focus our norms. We must not easily dismiss the culture-shaping form of technology. Those who choose the beginnings of a road also choose its destination. The issue of embryonic and germline genetic interventions concretises what we are getting at, regarding notions of unqualified autonomy, mastery over nature, and the flight from suffering and contingency.

We note at the outset that it would be near-impossible to discover the myriad undoubted benefits of heritable or germline gene editing without multi-generational tests, including the developing human in embryonic form. If there were fewer limits on the creation of embryos, e.g., allowing embryos to be genetically modified to study the relationship between genetic deficits, mutations and disease pathology, we would probably learn much more than we already know. The BAC consultation paper refers to a '14-day rule', a limit against developing human embryos for research after the 14th day of development. Raising the example of researchers in other countries calling for the 14-day rule to be doubled to 28 days, the BAC rightly deems this to be premature, and the BAC's position is that the 14-day limit should remain unchanged for now.³⁹

But should the 14-day rule stand? The question of the moral status of the early embryo is most clearly seen in pre-implantation genetic diagnosis and embryo creation for research. It is also relevant to germline gene therapy and editing because this would most certainly require the destruction of at least some embryos or the discarding of embryos in the case of unsuccessful procedures. The 14-day rule is sometimes built on arguments that before 14 days and the appearance of the primitive streak, the embryo is more akin to a mass of undifferentiated cells, each containing the potency to specialise into any cell in the body. Only after the appearance of the primitive streak does it become an organised whole with

³⁹ Bioethics Advisory Committee, *Human Nuclear Genome Editing*, 72.

the capacity to develop into a unique human individual. Because twinning also happens in the first 14 days, some argue that genuine personhood, and therefore the moral rights that accrue to the embryo, only starts after 14 days.⁴⁰ Another popular argument about personhood appeals to developmental notions of personhood, where an embryo grows into a person.⁴¹

As Roland Chia has explained, according to the Christian faith, human beings made in the image of God possess inviolable dignity and value from conception.⁴² The Church's stance is that the nascent human being in the form of an embryo is a human person even at the earliest stage. Any means that involves the creation, destruction, and/or the eugenic selection of human embryos is something we simply cannot support. All approvable therapy means should respect the inviolable life and bodily integrity of all individuals involved. Embryonic human beings, as living members of the species, must be included in the mutual networks of giving and receiving the likes of which every human being depends for existence and flourishing. Their good is as integral to the human good as is the good of others. Furthermore, we should not simply regard the embryo as just any person but recognise the embryo as someone's *child*.⁴³ The question of the status of the embryo, in Christianity, turns not only on the embryo's moral status but also on the networks of relations the embryo will be a part of throughout his or her life. Christianity, in the main, does not rely on prevarications of personhood because "to be willing to kill what for all one knows is a person is to be willing to kill a person."⁴⁴ For this reason, we disagree strongly with any destructive interference with the embryo, even surplus embryos created by IVF.⁴⁵ The status of the embryo demands our respect.

Some examples of what this might mean in practice would be that we treat embryos as patients and not mere experimental subjects. If interventions, especially genetic ones, are to be made at the level of embryonic life, they should, as a matter of course, be directly related to the safety and health of the embryo. In our view, this rules out the creation of embryos for the express purpose of genetic research. But even allowing for gene therapy at the level of embryonic life, our knowledge of what gene editing does to the embryo is still far too primitive and uncertain at this juncture for it to be commended. For example, Nada Kubikova reports that the cells of early human embryos often cannot repair damage to their DNA, which has implications for CRISPR gene editing. Kubikova's

⁴⁰ So, for example, Norman Ford, *When Did I Begin? Conception of the Human Individual in History, Philosophy and Science* (Cambridge: Cambridge University Press, 1988), 136.

⁴¹ This is the argument in Michael Tooley, *Abortion and Infanticide* (Oxford: Oxford University Press, 1984).

⁴² Roland Chia, "Embryo Editing", *ETHOS* (Feb 4, 2019), <https://ethosinstitute.sg/embryo-editing/> (accessed 20 Aug, 2024)

⁴³ O. Carter Snead, *What It Means To Be Human: The Case for the Body in Public Bioethics* (Cambridge, MA: Harvard University Press, 2020), 134.

⁴⁴ Germain Grisez, *The Way of the Lord Jesus: Living a Christian Life* (Quincy, IL: Franciscan Press, 1993), 497.

⁴⁵ As, for example, recommended in the Bioethics Advisory Committee, *Human Nuclear Genome Editing*, 75: "Researchers should consider using surplus embryos created through assisted reproduction treatment for HNGE research if the risks of procuring oocytes solely for such research outweighs the benefits." We note also that the later discussion (pp. 75ff) in the BAC paper of respect for persons and risks involved in embryonic research appear to operate on the premise that the embryo is not a person, since questions of risks to the embryo or respect for the embryo are not discussed.

report showed that in their study, 40% of double-stranded breaks caused by gene editing remained unresolved, eventually causing segmental abnormalities known to be detrimental to viability and higher risks of congenital abnormalities. In their view, “the results provide a warning against the therapeutic use of CRISPR-Cas9 in human embryos.”⁴⁶

One possible consequence of this discovery would be increasing attempts to correct genetic mutations upstream of fertilisation. But editing at this level casts into relief a whole host of other concerns. The shadow of eugenics writ large in the 20th century is certainly one concern. However, other concerns might be raised regarding cultural preferences, what constitutes genetic therapy or genetic enhancement, equitable access and resource allocation, and increased discrimination or stigmatisation for adopters or rejectors of such techniques. Is science and biotechnology simply the craft of manipulating, substituting, and deflecting the forces of nature? Surely not.

Returning, however, to the question of heritable germline editing, the NCCS simply notes that there is a profound Christian tradition of moral and theological reflection on human nature and human limits. This line of thinking is what we might broadly term the natural law tradition. This tradition teaches that we can discover, within our nature, obligations and laws that dictate our behaviour.⁴⁷ These truths of human nature are perennial because they are a metaphysically grounded basis for human nature and are thus integral to our understanding of what constitutes human flourishing and the design willed by God.⁴⁸ That is to say, humanity’s flourishing consists of the fulfilment of our shared human nature. The natural law is that which, if followed, will satisfy our inclinations in accord with reason and help actualise our definitive capacities.⁴⁹ Gene editing that alters our human nature has an inimical effect on our capacity to pursue the human good in terms of our flourishing. This is not to say that there is no horror in nature. Good medicine understands, respects, and treats that. But there is also plenty of order and significance in nature that is worthy of respect – including a healthy respect for limits. Would, for example, human eyesight be *truly* human if we could enhance our eyesight to the levels of animal eyesight?

Ronald Cole-Turner aptly states that “genetic engineering will change nature by altering the genetic arrangement inside living things” since it would alter the “inward principles that guide” human development, inward principles that once “set limits both physical and moral on our technological alterations.”⁵⁰ To place nature beyond human responsibility is simply to acknowledge the limits of our knowledge and powers. To

⁴⁶ Nada Kubikova *et al*, “Deficiency of DNA double-strand break repair in human preimplantation embryos revealed by CRISPR-Cas9”, *Human Reproduction* Vol. 38 No. 1 (2023).

⁴⁷ Joseph, “The Decline of Natural Law Reasoning: The Influence of Recent Cultural and Intellectual Currents on the Tradition,” *The National Catholic Bioethics Quarterly* 14.2 (2014): 245-255.

⁴⁸ Tham, “Resisting the Temptation”, 55.

⁴⁹ For a helpful treatment of this, see Richard Berquist, *From Human Dignity to Natural Law: An Introduction* (Washington, DC: Catholic University of America Press, 2019). The definitive natural law thinker in the Christian tradition is Thomas Aquinas, who discusses this at length in *Summa Theologiae*, in the so-called Treatise on law, IaIIæ, Q.90-108.

⁵⁰ Ronald Cole-Turner, *The New Genesis: Theology and the Genetic Revolution* (Louisville, KY: Westminster John Knox Press, 1993).

suppose that nature has a moral order and teleological purpose that we should respect is to impose limits on those powers. The Genesis account of humanity's fall tells us that nature became hostile and lost its moral order as a result of human acts; the temptation we have before us now is to use that knowledge and ponder the possibilities that await us as we attempt to reconstruct a second nature. Perhaps some boundaries, such as those that limit attempts to reform human nature in our image, constitute such a considerable hedge that, for all intents and purposes, research into changes to our human nature should be considered morally impossible.

Engineering the human genome, especially in relation to future generations, makes us increasingly responsible for human nature. The issue of the human future looms large in these questions. Christianity compels us to consider the moral severity of consequences to later generations. Should we genetically modify our children or modify in ourselves heritable genes that can be passed down to subsequent generations of progeny? C.S. Lewis warns us that what we call man's power over nature can often turn out in reality to be some men's power over other men, with Nature simply as the locus of the exercise of that power. "All long-term exercises of power... must mean the power of earlier generations over later ones."⁵¹ One way in which C.S. Lewis's warning might be helpful is in considering the mythology of parental rights over our children, especially in relation to heritable gene editing. Karl Barth, however, is surely right to remind Christians that

it is one of the consolations of the coming kingdom and expiring time that this anxiety about posterity... that we should and must bear children, heirs of our blood and name and honour and wealth... is removed from us by the fact that the Son on whose birth alone everything seriously and ultimately depended has now become our Brother. No one now has to be conceived and born. We need not expect any other than the One of whose coming we are certain because He is already come. Parenthood is now only to be understood as a free and in some sense optional gift of the goodness of God.⁵²

Thus, children are never really ours in an absolute sense. We do not own them, and we do not have sole preserve over the moral order of the future. Since children are gifts, genetic editing for restoring health or treatment should be seen as part of our moral responsibility to care for and nurture God's gift of children. Issues arise where children are regarded as the objects of production, which opens the door to genetic editing for enhancement, such as genetic engineering to enhance features of future children, to engineer novel features, and to revise behavioural tendencies, for example.⁵³ One might object that many of these technologies are a matter of science fiction, not science fact. But once more, we would reiterate an earlier point: moral vision and unmasking hidden idols are as crucial in Christian bioethics as are issues or cases. Ethical and policy discussion concerning the use or potential use of genetic technologies for these ends is already underway, and discussion on this also shapes the kinds of technology we aspire

⁵¹ C.S. Lewis, *The Abolition of Man* (New York: Macmillan, 1947), 69.

⁵² Karl Barth, *Church Dogmatics* III/4 (Edinburgh: T&T Clark, 1961), 266.

⁵³ A good discussion of this can be found in Roberta Berry, "The Posthumanist Challenge to a Partly Naturalized Virtue Ethics", in Mark Cherry, ed., *The Normativity of the Natural: Human Goods, Human Virtues, and Human Flourishing* (New York: Springer, 2009).

to create. The quest to develop better gene editing tools to precisely engineer children to engineer them in the ways mentioned above or to design new capacities is not conceptually unimaginable.

A final concern must be raised on this. Will the desire to grant advantages to our offspring through genetic enhancement potentially alter genetic inheritance in unpredictable ways? When we take up the project of shaping future generations in such a fundamental way, we cannot state with any degree of certainty what good or ill we may accomplish. Our understanding of the interactions among and between genes, gene expressivity, epigenetics and environmental factors is underdeveloped. There is a veil of ignorance about many of these. To be precise, we do not know what project we are undertaking.

Even if an enhancement – longer life expectancy, for example – is regarded as an intrinsic good, the question remains if the risks and uncertainties of off-target effects or long-term devastating genetic diseases released into the public have been considered. Virtues of solidarity and care for the common good are not always the priorities of a project aimed at freeing the individual from the vicissitudes of life. The NCCS expresses our firm conviction that policies and research in this area prioritise moral commitments to the present and future generations. There can be no societal obligation to provide non-natural endowments that may create new capabilities foreign to human nature.

The Impact on Justice and Society

Talk of future generations can sometimes disguise the painful reality of eugenics. It bears mentioning that the actual victims of eugenics are those silenced lives who will never be given the chance to exist. After all, “the investment of a genetic disease with the spectre of an inevitably terrible life and early death fuels the sense that genetic screening is not only necessary but the only possible response.”⁵⁴

Understandably, the mention of eugenics in genomic medicine and research seems unfairly offensive. After all, it must be made clear that there is nothing in the BAC consultation paper to suggest any move towards the kind of cruel eugenic atrocities perpetuated in human history. However, the BAC rightly picks up on how gene editing for screening and prevention of disease might require little innovation to be applied for genetic enhancement. This, they warn, might lead to the development of programs of preferential reproduction of more desirable humans, a development the BAC claims “borders on eugenics”.⁵⁵

But, perhaps even that is not far enough. Robert Song warns us that “eugenics may not so much have died as adopted a new mask” in “the pre-natal screening suite, the genetic counsellor’s office, the general practitioner’s surgery, the abortion clinic.”⁵⁶ Elof Carlson

⁵⁴ Rebecca Steinberg, *Bodies in Glass: Genetics, Eugenics, Embryo Ethics* (Manchester: Manchester University Press, 1997), 118.

⁵⁵ Bioethics Advisory Committee, *Nuclear Genome*, 84.

⁵⁶ Song, *Human Genetics*, 49-50.

disagrees that for contemporary genetic screening to be truly eugenic, carriers would have to be eliminated from a population, not just embryos. In his estimation, “the use of prenatal diagnosis with elective abortion does not constitute a eugenic procedure because it does not change gene frequency.”⁵⁷ But perhaps the impact on society is eugenic not only in the sense of terminating genetically compromised embryos or removing genes from a population but also in the sense that it assumes that genetically compromised lives are socially undesirable.

One related fear is that the advent of widespread genetic screening and therapies will lead to a society that sees genetic diseases as a condition to be avoided at all costs, even life itself. Broad acceptance of testing appears to be triggered by society and policymakers who generally support ending lives considered undesirable by genetic deficiencies. As we have sounded elsewhere, here is the phantasm of the Baconian Project once again. Here, we might discern a certain ableism from policymakers and researchers who have failed to recognise that the lives and abilities they enjoy are a matter of grace, not merit. Will there come a time when prenatal testing proves to be an ever-present reminder that those born with genetic pathologies for diseases take their place in society not by right but by having the luck to have parents who resisted the implied degeneracy of keeping them? Into such a culture, let the Church boldly declare to all persons – genetically compromised or not – that it is good that they exist. The existence of those diagnosed with genetic issues is good in itself, not because their presence exists for our sake, to work out our anxieties. Neither are they good because they deserve love or care, for they may be unreceptive to our attention. Instead, let the Church boldly declare that their presence in society is good, simply because they are there, the gift of a loving God who welcomes us all.

If their presence is good, then we will take steps to ensure that the development of HNGE in medical care and research does not come with an increase in discrimination or stigmatisation, for example. As discussed earlier, it is not inconceivable that people who do not subscribe to genetic screening or therapy, where they are readily available or accessible, may be accused of negligence. But what if the costs are prohibitively expensive, accessible only to the most well-off in society? Should the surging inequality evident elsewhere in society be introduced into the heritable human genome? Other forms of discrimination are possible. For example, sharing DNA genetic variance data impacts the costs of insurance premiums. Companies or governments could also use such data to make discriminatory decisions based on genetic codes – such as hiring employees genetically predisposed to be healthier, give more work hours, or have generally lesser health risks.

From here, the discussion naturally turns to questions of justice. How will the prohibitively expensive genetic research projects be funded - through public coffers or private funding? Subsidies, grants, and funding from public monies occasion concerns over opportunity costs over funding other projects. Overseers must be on guard not to privilege funding the most profitable forms of therapy over the most beneficial ones. We

⁵⁷ Elof Axel Carlson, *The Unfit: A History of a Bad Idea* (Cold Spring Harbor, NY: Cold Spring Harbor Laboratory Press, 2001), 370.

would also ask policymakers to pay far more attention to contributive justice by companies or researchers that gain disproportionate benefits from biotechnology. For example, advanced genetic technologies for enhancement would likely be developed in the private sector. This would result in them being measured more expensively than genetic therapeutics. François Baylis reminds us of Luxturna, the first gene therapy for an inherited eye disease approved in the United States. Luxturna was made available to the public in 2018, with an entry cost of USD 850,000. Baylis's "modest" speculation is that a somatic gene editing therapy could cost \$1,000,000 USD to cure a single-gene disorder.⁵⁸ This would virtually guarantee that genetic enhancements are only available to a narrow segment of society.

Related questions of justice and access follow. Would the purported economic benefits of patenting lead to hermetically sealed silos of resources that should be made available to a broader number of people? Access is not always fairly distributed throughout society. How would therapies be paid for, through health insurance or private wealth? Insurance providers are generally reluctant to cover high-technology services, as seen in the high cost and sometimes prohibitively long waiting periods for maternity coverage to take effect. New technologies are higher in risk, but also likely to be more lucrative. This could result in situations where genetic therapies are limited to narrow segments of society with the means to pay for the latest and most expensive treatments.

Therapy and Enhancement

The advent of wider applications and innovations in HNGE alerts us to the distinction between therapy and enhancement. Slowly but steadily the role of medicine has been extended, driven by our appetites and ambitions, to encompass dimensions of life not previously considered matters of health, altering and revising the very frame of nature. Increasingly, we expect from medicine not just freedom from disease but from all that is unattractive, imperfect, or inconvenient.

Although it may seem easy to draw the line between therapy and enhancement, this is not always the case. According to Nick Bostrum and Rebecca Roache, it is difficult to map therapies and enhancement to standard contemporary medicine and the type of medicine that will be practiced. They name, for example, palliative care, cosmetic procedures, and fertility treatments as examples where therapy and enhancement overlap. This is particularly true of interventions that reduce the probability of disease, such as vaccination. They opine that vaccination can be seen as the enhancement of the immune system, or the preventative therapeutic intervention against specific diseases.⁵⁹ Bostrum and Roache also list other issues with this distinction, such as the problem of defining what is normal due to the variance in presentation of capacities such as

⁵⁸ François Baylis, *Altered Inheritance: CRISPR and the Ethics of Human Genome Editing* (Cambridge, MA: Harvard University Press, 2019), 23.

⁵⁹ Nick Bostrum and Rebecca Roache, "Ethical Issues in Human Enhancement", in Jesper Ryberg, Thomas Petersen, and Clark Wolf, eds., *New Waves in Applied Ethics* (New York: Palgrave Macmillan, 2008): 120.

intelligence, even within a single person and that person's lifespan. They also discuss how internal an intervention must be before it is considered enhancement.⁶⁰

Distinguishing therapy from enhancement might be no easy task, but that does not mean that distinctions do not exist or are trivial. Gilbert Meilaender encourages Christians to be wary of expansive definitions of health, such as the 1946 World Health Organizations definition of health as "the state of complete mental and social well-being, and not merely the absence of disease or infirmity." The drawing of distinctions between therapy and enhancement are needed to prevent capitulating to a bioethics without limits other than the limits of technology.⁶¹ Pauline Tabaoda agrees, providing a helpful distinction between gene enhancement for the sake of significant therapeutic goal and gene enhancement *per se*, which requires consideration of the object of the act (enhancement of primary vs. secondary traits), the intention (enhancement *per se* vs. related to clear therapeutic goals) and the circumstances (associated risks, etc.).⁶² The benefit of this is to foreground, at the heart of HNGE, the dignity of the human person.

There may well be a case for enhancement, as in Bostrum and Roache's argument on the necessity of slowing ageing by investigating and altering senescence processes.⁶³ However, we strongly disagree that the ends justify the means. Neither are the means equivocally the same from the perspective of ethics. Biological manipulation is substantively different from environmental improvement in kind, not just degree, and genetic manipulation is so different as to appear to operate on another plane altogether. For this reason, the NCCS disagree with arguments for enhancement on purely hedonistic grounds or for the mere exercise of autonomy narrowly and individually construed. There cannot be a moral obligation to choose enhancement without due regard for classical moral considerations of purpose, consequences, virtues, and the common good, to name a few.

An example of this might be discerned from *Enhancing Human Capacities*, which rejects as "ideological" any understanding of enhancement that rests upon metaphysical concepts, and adopts a "welfarist" definition, in which an enhancement is "any change in the biology or psychology of a person which increases the chances of leading a good life in the relevant set of circumstances."⁶⁴ What the authors seem to completely miss is that the welfarist definition of leading a good life is also overtly ideological, and insofar as it is a definition of the kind of human good to be pursued, is equally susceptible to the accusation of being a metaphysical conception. There also appears to be in this definition a brusque reticence to consider theological and philosophical accounts for the human

⁶⁰ Ibid., 121-3.

⁶¹ Gilbert Meilaender, *Bioethics: A Primer for Christians* (Grand Rapids, MI: William B. Eerdmans, 2020), 39.

⁶² Pauline Tabaoda, "Human Genetic Enhancement: Is it Really a Matter of Perfection? A Dialog with Hanson, Keenan and Shuman", *Christian Bioethics* Vol. 5. No. 2 (1999): 195.

⁶³ Bostrum and Roache, "Human Enhancement", 123-4.

⁶⁴ Julian Savulescu, Anders Sandberg, and Guy Kahane, "Well-Being and Enhancement", in Julian Savulescu, Ruud ter Meulen and Guy Kahane, eds., *Enhancing Human Capacities* (Oxford: Wiley-Blackwell, 2011), 34.

good. One is reminded of the Baconian Project's stubborn rejection of grappling with how, if at all possible, suffering might be drawn into the ambit of the good life before the face of God.

Besides, if, as the authors suggest, the improvement sought is some good change, whether biological or psychological, then why is it not possible that the human good consists of a peaceful acceptance of bodily vulnerability, content with the practice and lifelong acquisition of the virtues (such as gratitude and humility)? And what about that definition results in turning to genetic enhancement as a matter of first resort?

Could it be that what is truly at work here is one of the consequences of the Baconian Project, as it has travelled through the centuries and embedded itself more firmly in the ethos and cultural consciousness of biotechnological research and ethics? Consider the language of gene "editing". As Paul Scherz shrewdly notes, "the metaphor of editing is much more consistent with the vision of the body that now drives molecular biology."⁶⁵ The body is seen to be a machine, a piece of software or textual information encoded in our genes that can simply be edited or reprogrammed as we see fit. Seen in this way, enhancements are simply software upgrades.

Yet a major obstacle stands in the way. The genome is not easily enhanced by editing. The ongoing discussion in this paper has cited strong evidence proving this. The idea that diseases could be traced to one or a few mutations faded when it was discovered that humans have fewer genes (about 20,000) than previously thought (about 100,000).⁶⁶ This means that they have to interact with each other to cause certain traits. To genetically enhance hearing, one would need to edit not just one gene, but hundreds. Complicating this further is that most genes have multiple functions, most of which are not yet known or understood by researchers.

The language of gene "editing" is only one manifestation of our desire to gain control over our bodies and offspring. It tends towards overly simplistic or reductive explanations of the body. But we should take to heart Scherz's witty suggestion that the body is "a living thing rather than a machine, flesh rather than text." If we think of the body as a text, let it not be a software programme but a work containing wisdom that must be engaged hermeneutically.⁶⁷ As a classic work requiring interpretation, so too is the body. Learning to interpret such an intricate text will require commentaries, corrections, or translations. Recovering older, wiser understandings of the body may help us garner the humble perspective needed to deal with HNGE in the face of the complexity of living things.

Conclusion

⁶⁵ Paul Scherz, "Editing the Body", *Humanum Review: Issues in Family, Culture and Science* 1 (2022)

⁶⁶ Iakes Ezkurdia and Michael Tress, *et al*, "The Shrinking Human Protein Coding Complement: Are There Now Fewer Than 20,000 Genes?"

⁶⁷ Scherz, "Editing".

We once again thank the BAC for their thought-provoking consultation paper and for inviting the NCCS to respond to it. The BAC recognizes that an irrevocably large and momentous human project such as HGNE must consider the vast wealth of human wisdom: social, political, scientific, philosophical, and, critically, moral and religious capital.

We acknowledge HNGE's incredible potential for human good and the breathtaking pace at which it continues to advance. The Church, too, is grateful for human ingenuity and innovation in genetic science. These advances “increasingly reveal the Creator’s greatness, because they allow man to discover the intrinsic order of creation and to appreciate the wonders of his body, in addition to his intellect, which to a certain extent reflects the light of the Word through whom ‘all things were made’ (*Jn* 1:3).”⁶⁸ It is easy for us to thank God for the many invaluable gifts He has bestowed on humanity, not least in the lives and creativity of the modern scientific community and enterprise. The work done by genetic science is a gift to mankind and can serve the common good.

Yet, as we have attempted to show, bioethics in the modern era can also be tempted by more dangerous aspirations, such as those in the Baconian project. The drive to relieve the human condition of all suffering, to master nature, and to increase the scope of the individual to choose whatever seems right to him, has led to a strong inclination to seek knowledge not so much for admiration or contemplation or pursuing the good, as for increasing power and control. Concerning the editing of the human genome, Pope John Paul II warned that such a mentality could lead to “interference with the internal structure of human life itself with a view to subduing, selecting and manipulating the body and, ultimately, the person and future generations.”⁶⁹

This danger is particularly acute in genetics since trust in technological and scientific progress in genetic science has taken on salvific proportions. But finitude and our propensity for wickedness cannot be eliminated by technology, and thus, salvation from suffering cannot finally be solved through science. The evil and sin that is part of human history shall endure until Jesus, the one in whom all things hold together, comes again in glory. For this reason, our gratitude for the remarkable progress that HNGE is accompanied by cautious advocacy.

In *Orthodoxy*, G.K. Chesterton shares an analogy of children playing football on a field atop a tall island in the sea. With walls built around the cliff’s edge, the game is boisterous and their enjoyment is unhindered. When the walls are taken down, leaving “the naked peril of the precipice”, the children do not fall over but are huddled in terror in the island’s centre. Chesterton’s point was that the walls constructed by Christianity are the “walls of a playground”.⁷⁰ They were there precisely to give the freedom of play,

⁶⁸ Pope John Paul II, *Address to the Pontifical Academy for Life* (Feb 1998), §3.

⁶⁹ *Ibid.*

⁷⁰ G.K. Chesterton, *Orthodoxy* (London: John Lane, 1909), 267.

safe in the knowledge that the ability to plunge into the threatening waters below was kept at bay.

If our response to HNGE has seemed cautious so far, it is because restraint and reflection are precisely what we counsel. Though it may seem counterintuitive, at this juncture of human progress and extraordinary potential, we agree with the proposals for “slow science”, which challenges the dominant culture of speed in science. It requires acknowledging our shared interest in the common good, viewing science as a public resource and thus a shared responsibility. Slow science requires a reflective, moral science that seeks to improve the human condition but also accepts the need for consensus-building from every sector of society – not just the scientific and medical community, pharmaceutical companies, and policymakers, but also patients, people with disabilities, members of the general public, and, importantly, religious communities.⁷¹

Now that the wondrous prospects of HNGE have appeared on the horizon, we must take the time to define the boundaries we are trying to defend with clarity and precision; we can open a wider arena of legitimate study without excessive fear of the dangers posed by a breach of the fundamental moral assumptions that sustain our civilisation. Our support for a slow science approach is especially suited for genomic research. The plurality of creative technologies needed to move forward on gene editing suggests that regulatory frameworks and legal guidelines will quickly become outdated in a failure to keep up-to-date with frontier science. It is well-recognized that research in emerging biotechnologies is characterised by uncertainty, ambiguity, and transformative potential—these present unique ethical and societal challenges with critical implications for policy and governance.

The Church is not against technology or advancement. To describe our stance in these categories is neither helpful nor particularly Christian. We are neither pure advocates nor opponents. We refuse to reduce our response to these categories because the moral vision we hold grants us the dignity, freedom, and responsibility to choose what is right and sound, and not only what is expedient or popular. We find our bearings in the givens of human life, the dignity of the human person, and our care for the common good, not just the individual. To repeat what we have said at the outset of this paper, the only irrelevance we fear is irrelevance to God.

In general, we find that interventions of a therapeutic nature can be morally acceptable if the process does not destroy or impede essential components and processes of human nature, such as the nature capacities outlined to us by the natural law tradition, and if other issues such as safety, efficacy, and the free, informed consent of future generations could be meaningfully addressed. This might include safeguards, speed bumps, more regulatory oversight, or stricter laws. In addition, we ask if society is truly free to refuse some forms or avenues of research in the name of human flourishing, or is becoming a genetically focused society inevitable?

⁷¹ Baylis, *Altered Inheritance*, 123-146.

In other words, the question of public bioethics of gene editing raises important and substantive questions about what it means to be human. What vision of humanity lives at the heart of our public reasoning? Is it a world where the person is atomised, solitary, and defined only by the capacity to pursue autonomous plans of his or her invention? Is it a world where nature and the human body are understood as merely inchoate matter to be harnessed and remade to relieve the human condition? Is technological transformation permissible, nay, required in the quest for happiness and human perfection? These are not questions one group in a plural society may impose on another. Still, they are questions worthy of our shared reflection and commitment to listen to one another.

As we offer our response, the NCCS is reminded of what Venter and Cohen, who coined the 21st century as the century of biology, had to say at the end of their agenda-setting article:

As it is, the scientist is focused on the task in front of him. He or she does not appreciate the bigger picture. The philosophers, on the other hand, rarely understand the science. Decision-makers are driven by political or stockholder expediency. Given the advancing state of science, this is a recipe for a catastrophe of the human essence. By the end of this century, the human genome project could be judged as the Manhattan Project of our time and us scientists as tinkering Frankensteins who couldn't leave well enough alone. Or, mapping the human genome could be judged as the greatest advance in the history of our species since we stood up on two legs.

Everything depends on the prudent application of the accumulated wisdom of human experience to the stunning new scientific discoveries of our age. Cognizant of both the great possibilities and risks knowledge of the human genetic code brings, our hope is that future generations will never have to ask, with T. S. Eliot, "Where is the wisdom we have lost in knowledge?"⁷²

Thomas Aquinas spoke of science as a gift, but also a gift that is chiefly concerned with *knowledge*, which is concerned with human or created things. For him, true wisdom comes from judging created things in the light of divine things.⁷³ Real happiness can come only from contemplating God, rather than from creaturely things, so creaturely goods cannot arouse spiritual joy except insofar as they are recognised as being charged with divine good. In this way spiritual peace and the resulting joy correspond directly to the gift of wisdom.⁷⁴ The bioethical challenges of the century of biology are manifold, but with humility for our frailty but confidence in the Lord, we offer these reflections as part of our God-given responsibility to give voice to and be a public witness of the Triune

⁷² Venter and Cohen, "Century of Biology", 77.

⁷³ Aquinas, *Summa Theologiæ* IIaIIæ, q.9.2.

⁷⁴ *Ibid.*, q.9.4.

God, for in the knowledge of the true God comes the wisdom to know and rightly discern created things.