A Child-Centred Approach in Human Heritable Genome Editing

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ABSTRACT

The core feature of human heritable genome editing ("HGE") is that any modification made on the germ cells (sperms or eggs) or early human embryos is likely to be passed down to subsequent generations. This feature makes the use of this technology highly controversial. Thus, there is a need to adopt a suitable approach to consider future children who are going to live the consequences of this technology. Taking a child-centred perspective, this thesis explores two main concerns: first, whether, and to what extent, the act of HGE is ethically acceptable; and second, how should HGE be regulated if it is deemed ethically acceptable for reproductive use. More specifically, it examines how a child-centred approach should be adopted in answering these questions.

This thesis first examines four child-related arguments commonly raised in the existing HGE debate, including the non-identity problem, the open future argument, the purported right to non-modified genomes, and the proposed long-term follow up system for the resulting children. It argues that the existing arguments and proposal have failed to appropriately consider (future) children's interests mainly because there is (1) a lack of solid theoretical framework to justify the recommendation commonly made for a health-related use of HGE, and (2) a lack of detailed analysis on an important but often overlooked concept in the HGE debate, that is the concept of "identity". In order to fill these gaps, this thesis explores the capability approach and argues that Jennifer Ruger's health capability paradigm provides a good philosophical framework in understanding why "health capabilities" can justify and more importantly, also limit the health-related use of the technology. Additionally, this thesis analyses the concepts of "identity" and argues for a multi-faceted understanding of "identity" with narrative identity to be given the greatest weight in the ethico-legal considerations of HGE.

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Chapter 1 – Introduction: Background, Motivation and Scope of This Thesis

This thesis is a conceptual and normative bioethical inquiry in respect of the possible reproductive use of human heritable genome editing, a type of biotechnology that allows scientists to alter the human genome before birth. The central concern of this thesis is the lack of proper attention to the interests of "children" in the current debate despite the fact that "children" are the ones who are directly affected by any consequences of this technology, should it be legalised in the future. My overall research project therefore explores the possibilities of adopting a child-centred approach in assessing the ethico-legal issues concerning the possible clinical use of this technology; and argues that the interests of "children" should be centralised in the future regulations of this technology, and that this can be achieved where a capability approach, together with a multi-faceted understanding of identity, is employed.

This chapter first provides a general background of this thesis, including defining some key terms such as "genes", "genomes", "somatic genome editing", "heritable genome editing" and "children", and identifies the reasons for conducting this research. It then outlines the research questions for this thesis and the scope within and beyond this research. Subsequently, this chapter provides a brief explanation of my research methodology, followed by an overview of the structure of this thesis.

1.1 An Overview of Human Heritable Genome Editing and Motivations for This Thesis

In the ethical debate concerning human genome editing, one of the common distinctions is between somatic intervention and germline intervention. The somatic-germline distinction can be traced back to 1982 when the then President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioural Research first published its extensive report on the ethical issues surrounding human genetic engineering.[1] To date, it is generally agreed that somatic

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[1] President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioural Research (President's Commission), *Splicing Life: A Report on the Social and Ethical Issues of Genetic Engineering with Human Beings* (Washington, DC 1982) 126.

intervention (that is, intervention on body cells of an existing patient) is ethically acceptable as long as it is subject to the necessary regulatory oversight, including obtaining informed consent from the patients.[2] Meanwhile, germline intervention (that is, intervention on reproductive cells and/or human embryos) is ethically controversial partly because any effects due to the intervention will be inherited by the next generations and only proxy consents of the parents are relevant (since it is not possible to obtain consent from unborn children).[3] Although this somatic-germline intervention distinction is not entirely without criticism,[4] Juengst opines that there is at least a well-defined conceptual line between these two types of interventions.[5] This thesis focuses on human heritable (germline) genome editing, not somatic genome editing.

1.1.1 "Genome editing": Linguistic clarification

Before understanding what "genome editing" means, it is worth clarifying the differences between the word "genome" and "gene". Humans have two types of genomes: nuclear genome (inherited both paternally and maternally) and mitochondrial genome (inherited only maternally).[6] The human genomes are made up of genes.[7] Genes are made up of deoxyribonucleic acid, or commonly known as the "DNA".[8] A DNA molecule is made up of double strands winding around one

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[2] See for instance, National Academies of Sciences, Engineering, and Medicine (NASEM), *Human Genome Editing: Science, Ethics and Governance* (The National Academic Press 2017) 109.

[3] Sarah Polcz and Anna Lewis, 'CRISPR-Cas9 and the Non-Germline Non-Controversy' (2016) Journal of Law and the Biosciences 413; for an overview of other arguments put forward on germline editing (e.g. the challenges for clinical practice; uncertainties and risks), see Martina Baumann, 'CRISPR/Cas9 Genome Editing – New and Old Ethical Issues Arising from A Revolutionary Technology' (2016) 10 Nanoethics 139.

[4] For instance, it is argued that the inheritable implications of somatic genome intervention are unclear, considering that some of the modified cells may affect the germ cells (reproductive cells) of the affected person and thereby pass on this effect to his/her future offspring. See for instance, Henry Greely, 'CRISPR'd Babies: Human Germline Genome Editing in the 'He Jiankui affair'' (2019) Journal of Law and the Biosciences 111, 114.

[5] Eric Juengst, 'Can Enhancement be Distinguished from Prevention in Genetic Medicine?' (1997) 22 The Journal of Medicine and Philosophy 125, 126.

[6] Leon Rosenberg and Diane Drobnis Rosenberg, *Human Genes and Genomes* (Elsevier 2012) 96 and 384.

[7] Ibid.

[8] Ibid, 75.

another.[9] There are four possible bases in between the strands: adenine (A), cytosine (C), guanine (G), or thymine (T).[10] Although "genome" and "gene" connote different meanings scientifically, they are often used interchangeably in the literature concerning genetic engineering.[11] Genome editing (or sometimes also referred to as gene editing) is a type of genetic technology that enables scientists to manipulate the DNA of an organism by adding, removing, or replacing certain genetic materials at particular spots in the genome.[12] Following the approach of the Nuffield Council on Bioethics ("Nuffield"), I use "genome" editing[13] instead of "gene" editing in this thesis because the former is more expansive. As Nuffield note, "genome" editing is not confined only to genes; it also includes making changes to the non-coding[14] areas of genomes and epigenomes.[15]

As indicated earlier, human heritable genome editing (hereinafter referred to as "HGE"), sometimes also known as human germline editing, refers to modifications of genes which bring heritable effects whereby the edited genes will be passed on to future generations (should the resulting individuals decide to have biological

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[9] For a more detailed understanding of DNA in scientific terms, see Leslie Pray, 'Discovery of DNA Structure and Function: Watson and Crick' 1 Nature Education 100 <https://www.nature.com/scitable/topicpage/discovery-of-dna-structure-and-function-watson-397/> accessed 28 December 2020; for a brief understanding, see Genetics Home Reference, 'What is DNA?' (*US National Library of Medicine*, 17 August 2020) <https://ghr.nlm.nih.gov/primer/basics/dna> accessed 28 December 2020.

[10] Ibid.

[11] The term "genetic engineering" (or, "genome engineering") is usually taken as an umbrella term to mean any intentional manipulation of genes/genomes and thus can cover both somatic and germline genome editing. See for instance, John Evans, *Playing God? Human Genetic Engineering and the Rationalization of Public Bioethical Debate* (University of Chicago Press 2002) 1.

[12] 'What is Genome Editing?' (*Your Genome*, 23 August 2017) <https://www.yourgenome.org/facts/what-is-genome-editing> accessed 29 December 2020.

[13] I am using the phrase "genome editing" in this thesis as it is extensively used in the debate, but it is worth noting that the choice of the word "edit" is not entirely free from controversy. See Meaghan O'Keefe and Others, '"Editing" Genes: A Case Study About How Language Matters in Bioethics' (2015) 15 The American Journal of Bioethics 3, 8 where the authors suggest that the word "editing" indicates improvement; they prefer more neutral terms such as "alter", "modify" and "change".

[14] Non-coding DNA does not provide instructions for generating proteins, but it is suggested that some of the non-coding DNA is fundamental to the cells' activity. Genetics Home Reference, 'What is Noncoding DNA?' (*US National Library of Medicine*, 17 August 2020) <https://ghr.nlm.nih.gov/primer/basics/noncodingdna> accessed 29 December 2020.

[15] Nuffield Council on Bioethics (Nuffield), *Genome Editing: An Ethical Review* (Nuffield Council on Bioethics 2016) para 1.3. Note: the epigenome consists of chemical compounds and proteins which control the functions of the DNA. See National Human Genome Research Institute, 'Epigenomics Fact Sheet' (16 August 2020) <https://www.genome.gov/about-genomics/fact-sheets/Epigenomics-Fact-Sheet> accessed 29 December 2020.

offspring in the future).[16] This technique involves editing of genes on our sperms or eggs (known as germ cells or gametes) or early human embryos.[17] Not all kinds of embryo editing are a form of germline editing. For instance, scientists may edit cells that have already been differentiated (cells that cannot become germline cells) in later stage human embryos.[18] Additionally, not all heritable human genome editing must involve embryos. For instance, edits of genes done on existing individuals may also bring (usually accidental) impact on their germ cells and may be passed on to their offspring.[19] The concern of this thesis is merely with those procedures carried out on human gametes or early human embryos for reproduction; hence, I will not consider the ethical implications of the inadvertent heritable effects caused by the genome editing performed on existing individuals (that is, somatic genome editing).

It must be noted that human genome editing in the current context, though also involves modification of genes, is not equivalent to having genetically modified organisms (or known as "GMOs"). GMOs may involve transgenic in which a particular gene is taken from one species and inserted in another species in order to gain a preferred trait.[20] In such an instance, the GMOs have genes that are from unrelated species. For example, corn has been genetically modified by inserting genes from a type of bacteria to be insect resistance.[21] GMOs are currently more prevalent in (but not confined to) the field of agriculture; and introducing it to the consumer market has sparked its own debate.[22] In this thesis, I do not deal with the concerns about GMOs. I use the words "modify", "alter" and "edit" genes (or genomes)

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[16] Supra note 2, NASEM (2017) 111.

[17] Ibid.

[18] Supra note 4, Greely (2019) 114.

[19] Ibid.

[20] Theresa Phillips, 'Genetically Modified Organisms (GMOs): Transgenic Crops and Recombinant DNA Technology' (2008) <https://www.nature.com/scitable/topicpage/genetically-modified-organisms-gmos-transgenic-crops-and-732/> accessed 29 December 2020.

[21] Ibid.

[22] See for instance, Michael Cardwell, 'The Release of Genetically Modified Organisms into the Environment: Public Concerns and Regulatory Responses' (2002) 4 Environmental Law Review 156.

interchangeably during the discussion to mean making changes to the DNA in the human genome without introducing any genes from other species.

1.1.2 Genome editing tools: Scientific background

The idea of editing the genes is not novel in that the very first genome editing tool can be traced back to around the 1990s. This includes the discovery of ZFNs and later, TALENs (around 2010),[23] whereby both involve engineered nucleases that bind to a specific sequence of DNA and make cuts on it.[24] The latest tool called CRISPR-Cas9,[25] first introduced in 2012, marks a massive leap in the field for it is allegedly quicker, cheaper and easier to use than the earlier approaches.[26] CRISPR-Cas9 works with guide molecules[27] that target a specific location in the genome and Cas9, an enzyme acting as a pair of "scissors" to cut both strands of the DNA sequence to allow changes to be made on the sequence. This technique depends on the cell's own repair systems to then mend the cuts in the DNA.[28] This last feature makes the eventual side effects unpredictable.[29] Since then, the techniques on CRISPR-Cas9 has (and will continue to be) expanded greatly. Recently, it is reported that other techniques developed from CRISPR-Cas9 known as base editing and prime editing drive even higher precision in genome editing. Both of these techniques allow edits of genes without the need to cut both strands of the DNA – prime editing allows scientists to cut only one (instead of both) strand of the DNA and insert the edited

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[23] ZFNs and TALENs stand for zinc-finger nucleases and transcription activator-like effector nucleases, respectively. See Srinivasan Chandrasegaran and Dana Carroll, 'Origins of Programmable Nucleases for Genome Engineering' (2016) 428 Journal of Molecular Biology 963.

[24] Thomas Gaj and Others, 'Genome-Editing Technologies: Principles and Applications' (2016) 8 Cold Spring Harbor Perspective in Biology a023754.

[25] CRISPR-Cas9 stands for clustered regularly interspaced short palindromic repeats (CRISPR) and its associated protein 9 (Cas9).

[26] Martin Jinek and Others, 'A Programmable Dual-RNA-Guided DNA Endonuclease in Adaptive Bacterial Immunity' (2012) 337 Science 816.

[27] It is the use of these guiding molecules (so-called RNA molecules) that makes the technique much cheaper compared to earlier techniques such as TALENs or ZFNs where both require protein engineering to target the DNA sequence in the genome: see Matthias Braun, Hannah Schickl and Peter Dabrock, 'Between Moral Hazard and Legal Uncertainty: An Introduction' in Matthias Braun, Hannah Schickl and Peter Dabrock (eds), *Between Moral Hazard and Legal Uncertainty* (Springer 2018) 3.

[28] Ibid.

[29] Heidi Ledford, 'Super-Precise New CRISPR Tool Could Tackle A Plethora of Genetic Diseases' (*Nature*, 21 October 2019) <https://www.nature.com/articles/d41586-019-03164-5> accessed 29 December 2020.

sequence back to it, hence reducing the unintended changes in the genome;[30] base editing, on the other hand, enables scientists to simply change one DNA letter (A, C, G or T) to another instead of cutting the strands of DNA.[31] Advancement in this area offers great prospects in targeting and modifying genes responsible for genetic disorders, including hereditary genetic diseases, with improved efficiency.[32]

- Progress made in human heritable genome editing

While the genome editing tools discussed above can be used in both somatic and germline (heritable) applications, it is worth further elaborating on its progress so far in its applications on human reproductive cells or early human embryos since this is the focus of my thesis. If proven safe and effective for human reproduction, this technique seems to have an added advantage to the available assisted reproductive technologies such as artificial insemination with donated sperms, and mitochondrial replacement technique ("MRT"),[33] which involve the genetic contribution of a third individual.[34] It is believed that HGE can be used in the future for prospective parents to have both genetically related and healthy children.[35] As I show, the notable scientific advancement made in this field, especially in these few years, signifies that the idea of having a human being who is genetically edited before birth is no longer fit only for the realm of science fiction.

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[30] Ibid.

[31] Heidi Ledford, 'Scientists Make Precise Gene Edits to Mitochondrial DNA for First Time' (*Nature*, 8 July 2020) <https://www.nature.com/articles/d41586-020-02054-5> accessed 29 December 2020; Heidi Ledford, 'Super-Precise CRISPR Tool Enhanced by Enzyme Engineering' (*Nature*, 10 February 2020) <https://www.nature.com/articles/d41586-020-00340-w> accessed 29 December 2020.

[32] Ibid, also see for instance, Liting You and Others, 'Advancements and Obstacles of CRISPR-Cas9 Technology in Translational Research' (2019) 13 Molecular Therapy – Methods & Clinical Development 359.

[33] This technique involves the replacement of unhealthy mitochondria in the mother's egg with healthy one from another woman's egg. I continue to use the terms "mitochondrial replacement technique" or "mitochondrial donation" throughout my thesis because these phrases have been used in most literature and official reports. But note, some have argued that "mitochondria replacement technique" is a misleading term when the procedure is in fact a "nuclear genome transfer". See for instance, Jeff Nisker, 'The Latest Thorn by Any Other Name: Germ-Line Nuclear Transfer in the Name of "Mitochondrial Replacement"' (2015) 37 Journal of Obstetrics and Gynaecology Canada 829; Francoise Baylis, 'Human Nuclear Genome Transfer (So-Called Mitochondrial Replacement): Clearing the Underbrush' (2017) 31 Bioethics 7.

[34] Rebecca Dimond and Neil Stephens, *Legalising Mitochondrial Donation: Enacting Ethical Futures in UK Biomedical Politics* (Palgrave Macmillan 2018) 137.

[35] Supra note 2, NASEM (2017) 111.

The very first attempt to edit human embryos using CRISPR-Cas9 was reported in 2015.[36] The experiment was conducted by a group of Chinese scientists using non-viable embryos, and the genes altered were accountable for a potentially deadly blood disorder.[37] The study revealed profound mosaic (where there is a mixture of cells with modified and non-modified genes that still carry the faulty genes supposed to be edited) and off-target (unintentional modifications in the genomes) effects in the embryos, therefore highlighting the need to further improve the technique of CRISPR-Cas9 before it can be introduced into the clinical setting.[38] Such research, being the first reported study in editing the genes of human embryos with possible heritable effects, created much controversy, with some appreciating the value of basic research and others warning of the possibility of creating a pregnancy.[39] In February 2016, there was a licence granted in the UK for carrying out research concerning the editing of genes on viable (rather than non-viable) human embryos using CRISPR-Cas9[40] and later in the same year, it was reported that a Swedish scientist had edited the genes of healthy human embryos.[41] In 2017, there was another attempt in China to edit the genes of viable human embryos using a newer form of CRISPR-Cas9.[42] The technique was allegedly more promising on normal cells

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[36] David Cyranoski and Sara Reardon, 'Chinese Scientists Genetically Modify Human Embryos' (*Nature*, 22 April 2015) <https://www.nature.com/news/chinese-scientists-genetically-modify-human-embryos-1.17378#/b1> accessed 29 December 2020.

[37] Puping Liang and Others, 'CRISPR/Cas9-Mediated Gene Editing in Human Tripronuclear Zygotes' 6 Protein & Cell 363.

[38] Ibid.

[39] Supra note 36, Cyranoski and Reardon (2015); see also Jocelyn Kaiser and Dennis Normile, 'Chinese Paper on Embryo Engineering Splits Scientific Community' (*Science*, 24 April 2015) <https://www.sciencemag.org/news/2015/04/chinese-paper-embryo-engineering-splits-scientific-community> accessed 29 December 2020.

[40] Gretchen Vogel, 'UK Researcher Receives Permission to Edit Genes in Human Embryos' (*Science*, 1 February 2016) <https://www.sciencemag.org/news/2016/02/uk-researcher-receives-permission-edit-genes-human-embryos> accessed 29 December 2020.

[41] Jessica Boddy, 'Swedish Scientist Edits DNA of Human Embryo' (*Science*, 22 September 2016) <https://www.sciencemag.org/news/2016/09/swedish-scientist-edits-dna-human-embryo> accessed 29 December 2020.

[42] Lichun Tang and Others, 'CRISPR/Cas9-Mediated Gene Editing in Human Zygotes Using Cas9 Protein' (2017) 292 Molecular Genetics and Genomics 525.

(though further improvement is still needed on the technique as there were still mosaic effects).[43] None of these studies involve any pregnancies.

Perhaps the most astonishing attempt thus far is the attempt made by scientist He Jiankui in November 2018 with the eventual live birth of twin girls, nick-named Lulu and Nana (hereinafter referred to as "scientist He's affair"). Using CRISPR-Cas9, scientist He edited the so-called CCR5 genes of two embryos to render them genetically resistant to human immunodeficiency viruses ("HIV") – a life-threatening condition that causes progressive failure to the immune system.[44] It was thought that functioning CCR5 genes could infect one's T-cells (that is, the white blood cells in the immune system); hence the deletion of the genes could prevent his/her T-cells from HIV.[45] However, this turns out to be more complicated than it was first thought. It is reported that the absence of CCR5 genes does not assure 'complete protection' to HIV as it only works for a certain form of HIV.[46] There is also research that associates CCR5 genes with protection from the influenza virus.[47] Furthermore, there is also evidence showing that modification of the CCR5 genes could have cognitive enhancement[48] and could improve recovery from strokes.[49] These suggest that the deletion of CCR5 genes might have other effects on the resulting individuals in addition to preventing them from contracting HIV. The experiment carried out by scientist He is deemed premature and it has been widely condemned. Scientist He has been convicted of 'illegal medical practice' and is now facing a fine and three

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[43] Ibid, see also Heidi Ledford, 'CRISPR Fixes Disease Gene in Viable Human Embryos' (*Nature*, 2 August 2017) <https://www.nature.com/news/crispr-fixes-disease-gene-in-viable-human-embryos-1.22382#:~:text=An%20international%20team%20of%20researchers,dozens%20of%20viable%20human%20embryos.> accessed 29 December 2020.

[44] For a detailed assessment of Scientist He's affair see, supra note 4, Greely (2019).

[45] Ibid, 117.

[46] Ibid, 158-159.

[47] William Glass and Others, 'Chemokine Receptor CCR5 Promotes Leukocyte Trafficking to the Brain and Survival in West Nile Virus Infection' (2005) 202 Journal of Experimental Medicine 1087.

[48] Antonio Regalado, 'China's CRISPR Twins Might Have Had Their Brains Inadvertently Enhanced' (MIT Technology Review, 21 February 2019) <https://www.technologyreview.com/2019/02/21/137309/the-crispr-twins-had-their-brains-altered/> accessed 29 December 2020; Miou Zhou and Others, 'CCR5 is a Suppressor for Cortical Plasticity and Hippocampal Learning and Memory' (2016) 5 eLife.

[49] Mary Joy and Others, 'CCR5 Is a Therapeutic Target for Recovery after Stroke and Traumatic Brain Injury' (2019) 176 Cell 1143.

years' imprisonment in China.[50] While the birth of the first genetically edited babies certainly astounded the world because the research was carried out unethically (partly due to the safety issues), it also reminds us that genome editing technology is fast-paced and is no longer a scientific fantasy. The calls for more regulations and governance,[51] including a call for a global moratorium for HGE,[52] are even more intense after scientist He's affair. Nevertheless, the scientific progress on the technique does not seem to have halted. For instance, it was reported in October 2019 that there is on-going research on editing of genes in human eggs to alter deaf genes by a Russian biologist, Denis Rebrikov; although it is reported that he will not create a pregnancy unless there is regulatory permission.[53]

In short, there has been remarkable progress made in the area of genome editing, especially with the discovery and development of CRISPR-Cas9. In October 2020, two scientists, Emmanuelle Charpentier and Jennifer Doudna, who discovered CRISPR-Cas9 were granted the Nobel Prize in Chemistry as recognition of the far-reaching impact of CRISPR-Cas9 on the life sciences.[54] While this certainly deserves celebrations, it is equally important to acknowledge the fears and concerns over genome editing technology, particularly those associated with HGE (discussed more below). It is both the promises and potential abuses of intentional alteration of the human genome, specifically those concerning the resultant children, that initiate this piece of research.

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[50] Shuang Liu, 'Legal Reflections on the Case of Genome-Edited Babies' (2020) 5 Global Health Research and Policy 1, 2.

[51] See for instance, Melanie Hess, 'A Call for an International Governance Framework for Human Germline Gene Editing' (2020) 95 Notre Dame Law Review 1369.

[52] Eric Lander and Others, 'Adopt A Moratorium on Heritable Genome Editing' (2019) 567 Nature 165 <https://www.nature.com/articles/d41586-019-00726-5> accessed 29 December 2020; see also World Health Organisation, 'Statement on Governance and Oversight of Human Genome Editing' (*WHO*, 26 July 2019) <https://www.who.int/news-room/detail/26-07-2019-statement-on-governance-and-oversight-of-human-genome-editing> accessed 29 December 2020.

[53] David Cyranoski, 'Russian 'CRISPR-Baby' Scientist Has Started Editing Genes in Human Eggs with Goal of Altering Deaf Gene' (*Nature*, 18 October 2019) <https://www.nature.com/articles/d41586-019-03018-0> accessed 29 December 2020.

[54] Heidi Ledford and Ewen Callaway, 'Pioneers of Revolutionary CRISPR Gene Editing Win Chemistry Nobel' (*Nature*, 7 October 2020) <https://www.nature.com/articles/d41586-020-02765-9> accessed 29 December 2020.

1.1.3 The controversies of human heritable genome editing

- The nature of the technology itself

There remain a lot of uncertainties in the clinical use of HGE, mainly because of the safety and technical issues. This is one of the reasons why scientist He's affair was widely criticised as premature.[55] It must be made clear here that, at the time of writing this thesis, the use of HGE is still not proven clinically safe for reproduction, although, as discussed earlier, there is increasing advancement in this field. The safety issues, in particular the off-target effects, mosaicism, on-target but unpredicted effects, are of great concern[56] (e.g. the twins born as a result of scientist He's conduct are purportedly exposed to a high risk of off-target effects).[57] Recently in September 2020, the National Academy of Sciences (NAS) recommended that there should be no pregnancy with genetically edited human embryos 'unless and until it has been clearly established that it is possible to efficiently and reliably make precise genomic changes without undesired changes' in the embryos.[58] It is further stated that 'these criteria have not been met' and further investigation would be necessary.[59]

Another feature of the technique which makes it highly controversial is its inheritable characteristics.[60] It is unlikely that such a procedure in the research setting will ever prove totally safe because the effect may only be known when it is tried on human beings.[61] The possible impact of changes done on the genome (e.g. unintentional consequences from the intended genome modifications) could be

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[55] Supra note 4, Greely (2019); see also, Jing-Ru Li and Others, 'Experiments that Led to the First Gene-Edited Babies: The Ethical Failings and the Urgent Need for Better Governance' (2019) 20 Journal of Zhejiang University Science 32 where the authors highlight a few ethical issues with scientist He's affair, including 'questionable scientific value, unreasonable risk-benefit ratio, illegitimate ethics review, invalid informed consent, and regulatory misconduct'.

[56] National Academy of Sciences (NAS), *Heritable Human Genome Editing* (The National Academies Press 2020) 7 (page number indicated is from the prepublication copy).

[57] Supra note 55, Li and Others (2019) 35.

[58] Supra note 56, NAS (2020).

[59] Ibid.

[60] Supra note 2, NASEM (2017) 6-7.

[61] Edward Lanphier and Others, 'Don't Edit the Human Germ Line' (2015) 519 Nature 410 where it is highlighted that 'the precise effects of genetic modification to an embryo may be impossible to know until after birth'.

multigenerational.[62] Additionally, there is no predicted time frame for the adverse effects (if any) to reveal themselves.[63] But, it is also alleged that as new techniques developed, the limitations of HGE can be significantly improved.[64]

When this happens, it is likely that HGE could eventually become feasible in the clinical settings for the (at least, initial) purpose of having a genetically related and healthy baby.[65] Noting this, the arguments made in this thesis work from the assumption that the time will come where the technique is safe and effective for reproductive purpose. Hence, this thesis will not further discuss the safety and technical issues in considering whether HGE is/should be ethically permissible or not. Instead, it focuses on the interests of "children" born as a result of the procedure.

- For the sake of children: a smokescreen?

While there is a heated debate on whether parents should be allowed to use HGE as a means of reproduction (more on this in Chapter 2), it must be stressed that the actual subjects of HGE are not the parents but the resultant children who are going to be born through the procedure and live with any subsequent consequences. Currently, discussions about "children" in the context of HGE are limited and unsatisfactory (see further Chapter 3). It is crucial to properly consider the interests of "children" in such a context in order to avoid them being used as a smokescreen to justify controversial technology such as HGE. Scientist He's affair is a good illustration of this concern. When asked during the panel discussion in the Second International Summit on Human Genome Editing 2018 in Hong Kong ("Second International Summit"), scientist He commented that he believes that there is an unmet medical need[66] in this case, not just for the twins but for millions of children

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[62] Supra note 2, NASEM (2017) 188.

[63] Ibid, 122.

[64] Ibid, Chapter 3 and Appendix A.

[65] Whether this purpose is justifiable in the context of HGE is debatable. Some have pointed out that there are already other alternatives which can provide means for parents to have healthy baby and genetically related (to at least one parent). See for instance, Tina Rulli, 'Reproductive CRISPR Does Not Cure Disease' (2019) 33 Bioethics 1072.

[66] This is another concern of HGE, but it is beyond the scope of this thesis. For a critical review regarding the 'pressing medical need' in the case of HGE, see for instance, Peter Mills, 'Genome Editing and Human Reproduction: The Therapeutic Fallacy and the "Most Unusual Case"' (2020) 63 Perspectives in Biology and Medicine 126. Mills thinks that it is reasonable to be sceptical about the claim that HGE can meet a pressing medical need. Yet, he suggests

since HIV vaccines are not available.[67] In this instance, the procedure is allegedly performed for the sake of children, with "children" presented as the beneficiaries of the procedure. However, I argue that the interests of the resulting children have not been adequately considered in scientist He's affair. First of all, scientist He's real motivations behind the research remain questionable – there is suggestion that he was motivated by 'personal fame and gain'.[68] Second, the potential risks in this instance have not been sufficiently weighed against the proposed benefits. As pointed out earlier, disabling CCR5 genes may cause other unintended consequences to the resulting babies. Furthermore, parents who are HIV-positive need not necessarily transmit the disease to their offspring as long as the parents are undergoing standard HIV treatment.[69] There are already more effective and accessible alternatives to prevent transmission of HIV to children (e.g. by using antiretroviral drugs and sperm washing).[70] Hence, preventing HIV transmission by germline modification brings only a small benefit to the resultant children while exposing them and their future generations to destructive implications due to the – at present – unpredictable and uncontrollable risks.[71] This example clearly demonstrates how easily the "interests of children" can be manipulated by the stakeholders (such as scientist He) in the field to mask the technical and socio-ethical challenges still associated with the technology. This observation further motivates this thesis to speak from a child-centred perspective (explained more below) when considering the ethico-legal questions related to HGE.

- *"Therapeutic" use in human heritable genome editing*

In justifying the clinical use of genome editing, the "therapeutic" use of the technology – that is, to eliminate or prevent transmission of genetic diseases –

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that this reason itself will not or should not necessarily preclude the eventual application of HGE for merely focusing on medical grounds fails to consider the interrelated interests of the wider society and its future members as well as the possible value of HGE.

[67] WGCethics, '29 Nov 2018 – International Summit on Human Genome Editing – He Jiankui Presentation and Q & A' <https://www.youtube.com/watch?v=tLZufCrjrN0> accessed 29 December 2020, approximately at 40:22-41:15.

[68] Supra note 4, Greely (2019) 142.

[69] Supra note 55, Li and Others (2019) 35.

[70] Ibid.

[71] Ibid.

appears a common and more acceptable ground.[72] This is, however, challengeable in the context of HGE for two reasons. First, it is doubtful whether the clinical implementation of HGE can indeed be categorised as "therapeutic". Rulli observes that the claim for "therapeutic" use for the reproductive purpose of germline modification is false and misleading.[73] This is because, as she argues, there is a lack of "counterfactual condition – a consideration of what would otherwise occur" that is usually seen in relation to therapeutic intervention.[74] According to Rulli, in the applications of HGE, the options for the parents are not merely between whether to use HGE to have a genetically healthy child or not to use HGE with a child possibly born with certain genetic diseases; but there is also another option for the parents – that is not having a child at all.[75] Hence, it is suggested that HGE is not therapeutic but rather reproductive since it involves bringing a child with certain preferred characteristics (say, without certain genetically related conditions) into existence.[76]

Second, even if we accept that HGE is therapeutic, it is also questionable whether being classified as a "therapy" can plausibly create an ethical boundary in deciding the clinical permissibility of the technology. As well as drawing a line between somatic and germline editing, another way of debating the use of human genome editing is to distinguish the technological use for therapy and enhancement.[77] A brief discussion of this issue will be helpful to better understand the overall ethical debate of HGE. In its simplest form, "therapy" can be understood as treating individuals with diseases or impairments with the aim of restoring them to a normal state of health and fitness (making something right); meanwhile, "enhancement" can be

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[72] See for instance, supra note 15, Nuffield Council on Bioethics (2016) chapter 4. Nuffield highlights the fact that researchers are now undergoing in-depth research on genome editing techniques with the aim of improving human health. Although it identifies several limitations on the techniques, such discussion no doubt indicates that improving human health (i.e., therapeutic purpose) could be a legitimate ethical ground for future clinical application of the techniques. See also, supra note 2, NASEM (2017) chapter 5.

[73] Supra note 65, Rulli (2019).

[74] Ibid, 1076. A straightforward example of this would be to consider whether a certain drug should be given to a patient. The patient may be in a worse off state if without being given the drug, hence there is a counterfactual condition in this instance.

[75] Ibid.

[76] Supra note 66, Mills (2020) 129.

[77] LeRoy Walters and Julie Gage Palmer, *The Ethics of Human Gene Therapy* (New York: Oxford University Press 1997).

understood as improving the "normal" functions of the human body or human capacities (making something better than well).[78] One of the dominant positions in the general debate relating to human genome editing is the claim that this technology is ethically acceptable for therapeutic uses but ethically questionable for enhancement purposes.[79] The former is deemed more ethically acceptable because of its association with medical purposes. It is long established that medicine aims to treat or prevent diseases, promote human health, and reduce human pain and suffering.[80] It is therefore argued that "therapeutic" uses of genome editing are within medical goals while enhancement uses are not.[81] This distinction may also be applied to HGE. Even scientist He has seemingly adopted such distinction when he, in the panel discussion during the Second International Summit, explicitly expressed that he is 'against enhancement' in response to the concern that the CCR5 gene may have "enhancement" effects on cognitive function.[82] It seems that scientist He has sought to distance himself from "enhancement" use of HGE, indicating that such use is ethically questionable.

Nonetheless, it is claimed that drawing a line between therapy and enhancement does not enable us to determine the moral acceptability and unacceptability of the technology. For instance, Resnik argues that there is no moral significance of such distinction because not all medical therapy is inherently morally acceptable[83] and not all enhancement is morally problematic.[84] It is also suggested that the distinction between therapy and enhancement is made on the misleading assumption that health, disease and normality can be properly defined when in fact, all of these

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[78] See for instance, David Resnik, 'The Moral Significance of the Therapy-Enhancement Distinction in Human Genetics' (2000) 9 Cambridge Quarterly of Healthcare Ethics 365.

[79] See for instance, French Anderson, 'Why Draw A Line?' (1989) 14 Journal of Medicine and Philosophy 681; Patricia Baird, 'Altering Human Genes: Social, Ethical and Legal Implications' (1994) 37 Perspectives in Biology and Medicine 566; Ronald Green, 'Last Word: Imagining the Future' (2005) Kennedy Institute of Ethics Journal 101; and more recently discussed in Barry Coller, 'Ethics of Human Genome Editing' (2019) 70 Annual Review of Medicine 289.

[80] Supra note 78, Resnik (2000) 368.

[81] See supra note 79, Anderson (1989); Baird (1994).

[82] Supra note 67, WGCethics (2018) approximately at 28:10-28:12.

[83] For instance, therapy which is deemed risky to others due to technical limitations is not justifiable.

[84] Supra note 78, Resnik (2000) 374.

concepts are highly subjective and thus subject to various interpretations.[85] Following Boorse, "health" and "disease" are descriptive conceptions where they are fact-based underpinnings in human biology.[86] So when an organism is diseased, it means that there is a deviation from the "normal functioning" of the specific species. In other words, the diseased organism is no longer healthy as it lacks the functional capacities of a "normal" member of its species.[87]

Boorse's descriptive account of health is frequently contrasted with a more subjective interpretation of health and disease in which it is argued that health and disease are socially, morally and culturally constructed.[88] For instance, homosexuality was once categorised as a mental disorder and homosexual behaviours were deemed abnormal.[89] This also indicates that being healthy is seen as being normal and "normal" here can mean "a defined standard" – being free from disease is thus in one's normal state.[90] But Dupre reminds us that whether one is considered "normal" relies on the cultural and technological background of that person. He exemplifies that deaf people may be deemed abnormal in a non-deaf community, but it may be deemed normal in a deaf community. Hence, the normality of a person can be said to depend on which context he/she belongs to.[91] This thinking is in line with the social model of disability in which it emphasises that individuals are disabled due to the societal barriers, not bodily impairment.[92] This shows that the concept of

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[85] See for instance, Alexander James McKeown, 'Re-Thinking the Distinction between Therapy and Enhancement: A Study in Empirical Ethics' (Doctorate Thesis, University of Bristol, December 2013) chapter 1; supra note 78, Resnik (2000).

[86] Christopher Boorse, 'On the Distinction between Disease and Illness' (1975) 5 Philosophy & Public Affairs 49; Christopher Boorse, 'Health as A Theoretical Concept' (1977) 44 Philosophy of Science 542.

[87] Ibid.

[88] See for instance, George John Agich, 'Disease and Value: A Rejection of the Value-Neutrality Thesis' (1983) 4 Theoretical Medicine 27.

[89] American Psychological Association, 'Report of the American Psychology Association Task Force on Appropriate Therapeutic Responses to Sexual Orientation' (2009) <https://www.apa.org/pi/lgbt/resources/therapeutic-response.pdf> accessed 29 December 2020, 21.

[90] Michael Bess, 'Enhanced Humans versus "Normal People": Elusive Definitions' (2010) 35 Journal of Medicine and Philosophy 641, 645.

[91] John Dupre, 'Normal People' (1998) 65 Social Research 221, 234.

[92] For a thorough discussion on the social model of disability, see for instance, Bill Hughes and Kevin Paterson, 'The Social Model of Disability and the Disappearing Body: Towards A Sociology of Impairment' (2010) 12 Disability & Society 325.

normality may not be the best tool to distinguish therapy and enhancement because it is hard (if not impossible) to come out with a principled approach of determining a "normal" standard needed for therapy and enhancement, a concern also expressed by Bess.[93]

In addition, the concepts of "therapy" and "enhancement" are in themselves problematic. The question of whether the improvement of one's immune system should fall under "therapy" or "enhancement" clearly illustrates the blurred line between therapy and enhancement. Juengst points out that some human gene "therapy" (albeit in the somatic, non-heritable, context) works by enhancing the ability of certain genes to fight against cancerous cells or boost a stronger immune system to fight against the diseases.[94] Hence, if we agree that disease prevention is a notable goal within the medicine domain, then the use of human genome editing to *improve* human health systems and capacities will help reach that goal. This makes the therapy-enhancement distinction unable to define the ethical limits of proper use of the human genome editing technique.[95] One example would be vaccinations. Vaccinations are commonly employed for a medical goal and its main function is to improve the subjects' immune system so as to protect them against various infections. The vaccination case, again, demonstrates the vagueness between therapy and enhancement. This leads us either (1) to accept that vaccinations are under medical terrain and thus fall under legitimate "therapy";[96] or (2) to argue that vaccination is an exceptional example for enhancement – showing that not all types of enhancement are ethically problematic.[97] Following this understanding, it is arguable that the therapy-enhancement distinction is seemingly

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[93] Supra note 90, Bess (2010). Bess questions the concept of normality as what could be normal in one culture could be otherwise in another. For instance, as Bess asks, what is a "normal" height? The answers may vary according to different background/context.

[94] Supra note 5, Juengst (1997) 127.

[95] Ibid, 126.

[96] See Maxwell J Mehlman, Jessica Berg, Eric Juengst and Eric Kodish, 'Ethical and Legal Issues in Enhancement Research on Human Subjects' (2011) 20 Cambridge Quarterly of Healthcare Ethics 30 where "treatments" are defined by interventions including those that can improve human capacities in a way that regains or maintains health. Following this, Erler points out that this definition can include preventive interventions like vaccines (albeit he argues that it is not possible to distinguish preventive intervention from enhancement), see Alexandre Erler, 'The Limits of The Treatment-Enhancement Distinction as A Guide to Public Policy' (2017) 31 Bioethics 608, 609.

[97] Michael Morrison, 'STS and Enhancement Technologies: A Programme for Future Research' (2015) 28 Science & Technology Studies 3, 19.

blurred in scientist He's affair. In his attempt to edit the CCR5 genes, one can validly ask whether such an attempt is indeed a form of therapy with medical purpose or a form of enhancement that prevents a disease? This again reaffirms that the therapy-enhancement distinction is inadequate in guiding decision making in terms of the clinical acceptability of HGE. Therefore, due to the conceptual and normative uncertainties identified above, the ethico-legal debate on HGE should go *beyond* the therapy-enhancement distinction. Taking this into account, this thesis aims to develop a theoretical framework that can guide decisions in the ethical acceptability of the clinical use of HGE which is built upon the capability approach (see Chapter 4). This framework, in line with a child-centred perspective, is essential in ensuring that HGE is used with proper consideration of the lives of the resulting children and thus avoids "children" being taken for granted to justify this controversial technology. Before defining the research questions and scope of this thesis, it is worth understanding the current regulations on germline genome editing in the UK.

1.1.4 Regulatory landscape of human heritable genome editing in the UK

The UK has a regulatory framework on the use and research of human embryo which is permissive yet strictly scrutinised.[98] The use of HGE falls under the governance of the Human Fertilisation and Embryology Act 1990 (as amended in 2008) under the oversight of the Human Fertilisation and Embryology Authority ("HFEA"). Research on embryos, including using CRISPR techniques, is legal in the UK under the 1990 Act (as amended in 2008) as long as they are not implanted for pregnancy. Sections 3 and 11 of the Act provide that research involving human embryos is subject to a mandatory licence. As suggested earlier, in February 2016, the HFEA granted the first licence permitting genome editing on healthy human embryos for research purposes.[99]

The clinical or reproductive use of HGE is currently prohibited in the UK. Section 3ZA(4) provides that a permitted embryo is one where no nuclear or mitochondrial

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[98] David Reubi, 'Re-moralising Medicine: The Bioethical Thought Collective and the Regulation of the Body in British Medical Research' (2013) 11 Social Theory & Health 215.

[99] Ewen Callaway, 'UK Scientists Gain Licence to Edit Genes in Human Embryos' (*Nature*, 1 February 2016) <https://www.nature.com/news/uk-scientists-gain-licence-to-edit-genes-in-human-embryos-1.19270> accessed 29 December 2020.

DNA of any cell of the embryo has been altered. An exception to this is provided in Section 3ZA(5) in which a procedure involving changes in mitochondrial DNA to prevent the transmission of serious mitochondrial diseases is permitted. In short, in the UK, heritable genome editing for reproductive purposes is currently prohibited under the 1990 Act (as amended in 2008) except when it is done on the mitochondrial genome (rather than nuclear genome) for the prevention of mitochondrial diseases.[100] The legalisation of modification of mitochondrial DNA in the UK has made it the first country globally to allow a procedure in the reproductive setting that carries heritable effects (albeit only through the maternal line). Adashi and Cohen suggest that the UK policy on MRT may be a global precedent for other related technologies such as HGE.[101] However, such a policy is contentious, particularly on the view taken by the UK in interpreting "genetic identity" in the policy debate.[102] This observation is the basis for my investigation into the possible interpretations of "identity" (including "genetic identity") in the context of HGE and how a thorough understanding of "identity" can better safeguard children's interests (discussed more in later chapters).

UK biomedical research is not only subject to national rules and regulations but also several international obligations in relation to the safety and risks of research.[103] For instance, Article 3(2) of the Universal Declaration on Bioethics and Human Rights (adopted by the United Nations Educational, Scientific and Cultural Organisation "UNESCO" in 2005) provides that the interests and welfare of the individual should be prioritised over science or society. Article 4 further states that the benefits to patients or other individuals involved, be it direct or indirect, should be maximised with any possible risks to them kept to the minimum. Article 16 commits to protect future generations by stating that 'the impact of life sciences on future generations, including on their genetic constitution, should be given due regard'. Article 20 provides that there should be an appropriate risk assessment and management related to biosciences. Another international document worth noting is the Universal

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[100] Human Fertilisation and Embryology (Mitochondrial Donation) Regulations 2015.

[101] Eli Adashi and Glenn Cohen, 'Going Germline: Mitochondrial Replacement as A Guide to Genome Editing' (2016) 164 Cell 832.

[102] I will discuss more on this in Chapter 6.

[103] UK Parliament, 'Human Germline Genome Editing' (Postnote No. 611, January 2020).

Declaration on the Human Genome and Human Rights (issued by UNESCO in 1997). Article 5(a) similarly requires that assessment of the potential risks and benefits to be carried out before any research affecting one's genome shall be undertaken. Article 10 stresses that no research or research applications involving the human genome should prevail over respect for the human rights, freedoms and dignity of individuals or groups. Article 12(b) further states that the research applications relating to the human genome should aim to relieve human suffering and improve the health of individuals and humankind. It should be emphasised here that once a State has signed and ratified a treaty, it is bound to act in accordance with it.[104] Thus, there is a positive obligation on the part of the State under international law to adapt its national legislation in observing its undertakings.[105] This is relevant considering that the UK is a member of UNESCO. Although the Universal Declarations are not legally binding, it is deemed a customary international law whereby the member states are responsible to integrate the declarations' provisions into their domestic rules, regulations or policies.[106] All of the above do not, however, specifically outline their position on the use of HGE. The ban on clinical applications of HGE is more explicit in the Oviedo Convention 1997.[107] Nonetheless, the UK has not ratified nor signed this Convention. Hence, the UK is not bound by the prohibition under the Convention, although it is still bound to the customary obligations in relation to genome editing aforementioned.[108]

Thus far, it should be clear that this thesis, while acknowledging the development made in the field of genome editing, draws attention to the controversies surrounding HGE and highlights its concerns over the resulting children. As the discussion above may have suggested, HGE is currently positioned within a

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[104] Vienna Convention on the Law of Treaties (adopted 22 May 1969, entered into force 27 January 1980) 1155 UNTS 331, Article 26.

[105] Rumiana Yotova, 'The Regulation of Genome Editing and Human Reproduction Under International Law, EU Law and Comparative Law' (June 2017) <https://www.nuffieldbioethics.org/assets/pdfs/GEHR-report-on-regulation.pdf> accessed 29 December 2020, 33.

[106] Adele Langlois, 'The UNESCO Universal Declaration on Bioethics and Human Rights: Perspectives from Kenya and South Africa' (2008) 16 Health Care Analysis 39, 40.

[107] Also known as the Convention on Human Rights and Biomedicine (adopted 4 April 1997, entered into force 1 December 1999). See Article 13, I will revisit this Article in Chapter 3.

[108] Supra note 105, Yotova (2017) 33.

"therapeutic" setting in which "children's interests" and "health" are often presented as potential justifications for an ethical use of HGE. Nevertheless, careful attention should be given to such positionings to ensure that they are not merely a form of language used tactfully by the stakeholders to embellish the socio-ethical challenges of the technology, and that the interests of the resultant individuals are properly considered. These observations motivate this research with the following research questions.

1.2 Research Questions

Against the above background, this thesis addresses the main research question as follows:

> Why should and how might a child-centred approach be adopted to govern the reproductive use of HGE and ensure the interests of future children are adequately considered and safeguarded?

In order to answer this research question, this thesis will examine the following questions:

> a. How are "children" addressed within the current ethico-legal debate on HGE? What are the gaps in the existing child-related arguments made in the HGE debate? **(Chapter 3)**
>
> b. Drawing from the answers to above questions, how a theoretical framework – in line with a child-centred approach – could address the gaps in the current recommendation made for the clinical use of HGE, that is to prevent serious genetic diseases? **(Chapter 4)**
>
> c. How is the concept of "identity" relevant to a child-centred approach? How would a child-centred identity-based approach inform the ethical debates surrounding HGE? To what extent could and/or should such an approach shape the legal regulation of HGE? **(Chapters 5 and 6)**

1.3 Scope of This Thesis

As the discussion in section 1.1 indicates, the ethico-legal debates concerning HGE cover a wide range of issues. In this section, it is therefore necessary for me to set out what this thesis covers and what issues are beyond its scope.

1.3.1 Heritable genome editing on nuclear genome

The legalisation of MRT in the UK,[109] which involves modification of the mitochondrial genome, suggests that it is possible to distinguish the technological use for editing the nuclear genome from the mitochondrial genome. Such a distinction is apparent in the policy debate with respect to the clinical applications of MRT, where altering the nuclear genome is frequently regarded as more ethically problematic than editing the mitochondrial genome.[110] This is because the former allegedly has more significant implications on the resulting individuals' "personal identity"[111] (further detail in Chapter 5). This thesis concerns the ethico-legal issues on the modification of nuclear genome. This being said, the existing debate on MRT will be referred to in order to facilitate some of the arguments made in this thesis. Although MRT technically also causes heritable effects, when I refer to human heritable genome editing (or "HGE"), I mean the editing done on the nuclear genome.

1.3.2 Heritable genome editing for prevention of genetic diseases

In my thesis, I avoid the terms "therapy" and "treatment" because, as indicated earlier, it is indeterminate whether HGE should (or can) be classified as "therapy" or "treatment" since there is no *existing* individual patient to be *treated* in such a context. Rather, HGE is about creating certain kinds of children, including children free from certain genetic diseases. My thesis thus focuses on the reproductive use of

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[109] See supra note 33 for an explanation of MRT.

[110] Human Fertilisation and Embryology Authority, HFEA, 'Mitochondrial Replacement Consultation: Advice to Government' (March 2013) para 6.69; also, Department of Health, Health Science and Bioethics Division, 'Mitochondrial Donation: A Consultation on Draft Regulations to Permit the Use of New Treatment Techniques to Prevent the Transmission of a Serious Mitochondrial Disease from Mother to Child' (2014) <https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/285251/mitochondrial_donation_consultation_document_24_02_14_Accessible_V0.4.pdf> accessed 29 December 2020.

[111] Ibid. For an academic discussion, see for instance, John Appleby, 'Should Mitochondrial Donation Be Anonymous?' (2018) 43 Journal of Medicine and Philosophy 261.

the technology for the *prevention* of transmission of genetically related diseases, including the prevention of transmission of diseases by improving the body's immune system (I refer to this in this thesis as "preventive intervention" or "health-related use"). My thesis does not cover the use of technology for the purpose of enhancement, by which I mean (following Bess' definition) "an intervention designed to modify a person's traits, adding qualities or capabilities that would not otherwise have been expected to characterise that person",[112] that is, modifying personality or behavioural traits such as intelligence, shyness, aggression and athletic ability.[113] My thesis also does not cover transhumanism[114] – an idea usually raised in human enhancement debate in which it involves a vision with post-humans who are beings with "vastly greater capacities than present human beings have."[115]

There are three reasons why I focus on preventive intervention (thus, drawing a blurred line between preventive intervention and enhancement) in this thesis. First, the process of enhancement is far more complicated than preventive medicine. The enhancement candidate traits such as the behavioural traits aforementioned, though widely cited in the human enhancement debate, are arguably not likely to be achievable. For instance, Rosoff questions the scientific plausibility of genetic enhancement of human behavioural traits because, as it is argued, such a claim is based on (1) a flawed assumption that such a notion can turn into reality when in fact it is unlikely possible due to the 'complexity of phenotypic expression' and (2) an over-reliance on genetic determinism for supposing that the traits can be 'causally directed by specific genes'.[116] In any event, even if it is possible to specify the genes for enhancement of personality traits, these personalities are gradually cultivated in social processes like child rearing, education and training.[117] Likewise, Malmqvist

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[112] Supra note 90, Bess (2010) 643.

[113] See for instance, Philip M Rosoff, 'The Myth of Genetic Enhancement' (2012) 33 Theoretical Medicine and Bioethics 163.

[114] This is a movement which seeks to evaluate opportunities to enhance human condition by technological advances. As defined by Nick Bostrom in Nick Bostrom, 'Human Genetic Enhancements: A Transhumanist Perspective' (2003) 37 The Journal of Value Inquiry 493.

[115] Ibid, 493.

[116] Supra note 113, Rosoff (2012).

[117] Erik Malmqvist, 'Reproductive Choice, Enhancement, and the Moral Continuum Argument' (2014) 39 Journal of Medicine and Philosophy 41, 47.

reminds us to consider the *likelihood of materialising* the envisioned outcome when contemplating the enhancement use of genome editing technology.[118] In particular, he suggests that it is misguided to assume that disease prevention and enhancement can proceed with equivalent precision.[119] There are a wider set of socio-ethical concerns when HGE is employed for enhancement purpose – a task beyond the scope of this thesis.[120]

Second, in principle, such a distinction between "preventive intervention" and enhancement may be useful in the relevant policy making. Bess claims that it is not entirely meaningless to distinguish the concepts of "therapy" and "enhancement" despite the conceptual muddles for such distinction. He urges that it is the *awareness* that there is 'no perfectly solid ground' that is important.[121] In fact, Resnik argues that the therapy-enhancement distinction can guide public policy for it helps to establish 'moral zones without any sharp boundaries'.[122] Such a distinction may be able to address our hope for preventing diseases and promoting good health and our fear of undesirable consequences from enhancement.[123] In addition to this, I argue that the distinction can be justified by the principle of legal certainty.[124] It is the notion that the legal rules and regulations must be adequately comprehensible so that people can make autonomous choices about their own conduct at the same time as avoiding unnecessary, arbitrary exercise of government authority.[125] As Lord Mance said, 'the law should be certain, so that it can be easily enforced and so that

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[118] Ibid, 46.

[119] Ibid.

[120] See for instance, Ronald Lindsay, 'Enhancements and Justice: Problems in Determining the Requirements of Justice in a Genetically Transformed Society' (2005) 15 Kennedy Institute of Ethics Journal 3.

[121] Supra note 90, Bess (2010).

[122] Supra note 78, Resnik (2000) 374.

[123] Ibid.

[124] Note that the principle of legal certainty is not without any criticism. See for instance, Patricia Popelier, 'Five Paradoxes on Legal Certainty and the Lawmaker' (2008) Volume II Legisprudence 47.

[125] Mark Fenwick and Stefan Wrbka, 'The Shifting Meaning of Legal Certainty' in Mark Fenwick and Stefan Wrbka (eds), *Legal Certainty in a Contemporary Context* (Springer 2016).

people can know where they stand'.[126] Thus, when the law seeks to identify what should be done with regard to HGE in the reproductive setting and what should not be done (even if it is a rough moral zone), there would be reasonable expectations by the subjects (in this context, the scientists, the medical practitioners, the commercial companies, the community, the parents) that their duties and rights would be applied consistently. By distinguishing medical reasons (health-related purposes) from non-medical reasons, the law can at least provide a threshold for legitimate and non-legitimate use of a particular technology. There are already such practices in the current law and regulations. For instance, as discussed earlier in section 1.1.4, in the UK, MRT is legally allowed in the reproductive setting only for the prevention of transmission of severe mitochondrial diseases.[127] Furthermore, preimplantation genetic diagnosis (PGD), another assisted reproductive technology that allows screening of embryos and subsequent selection of wanted embryos for implantation, may be legally used for medical reasons to prevent serious genetic diseases. PGD for sex selection is (at least in the UK)[128] not allowed except where it is to prevent a serious hereditary sex-related disease.[129]

Third, there is a strong policy reason for having clear regulations on what is legally permissible and what is not. This is necessary to avoid over-burdening the medical profession. If it is agreed that HGE can be ethically used in human reproductive

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[126] Lord Mance, 'Should Law Be Certain?' (2011) <https://www.supremecourt.uk/docs/speech_111011.pdf> accessed 29 December 2020. Note that Lord Mance acknowledges that uncertainty is also part of the law, for instance one person's certainty is the other's doubts. Yet still, Lord Mance opines that there should be some identified fundamental societal values and that the law should not be neutral (see para 47). See also, Lord Bingham, 'The Rule of Law' (2007) 66 Cambridge Law Journal 67, 69 where Lord Bingham outlined some core principles of the rule of law which include that the law must be 'clear and predictable'.

[127] Human Fertilisation and Embryology (Mitochondrial Donation) Regulations 2015; Note however, in other countries like Greece, this therapy has been extended for infertility treatment. See Catherine Heffner, 'First Baby Born in Mitochondrial Donation for Infertility Trial' (*BioNews*, 15 April 2019) <https://www.bionews.org.uk/page_142476> accessed 29 December 2020.

[128] There are treatment centres in other countries that offer gender selection methods, for example, the United States, Thailand, Mexico and Italy. See Shivali Best, 'Controversial 'Gender Selection' Technique Lets You Choose the Sex of Your Baby - But Should It Be Allowed?' (*Mirror*, 6 April 2018) <https://www.mirror.co.uk/science/controversial-gender-selection-technique-lets-12310362> accessed 29 December 2020.

[129] Human Fertilisation and Embryology Act 1990 (as amended in 2008) Schedule 2, section 1ZA; Parliamentary Office of Science and Technology, 'Sex Selection' (July 2003) <https://www.parliament.uk/documents/post/pn198.pdf> accessed 29 December 2020; Human Fertilisation and Embryology Authority (HFEA), *Code of Practice 8th Edition* (Revised October 2017) <https://www.hfea.gov.uk/media/2062/2017-10-02-code-of-practice-8th-edition-full-version-11th-revision-final-clean.pdf> accessed 29 December 2020, see Guidance Note 10 on embryo testing and sex selection.

settings, doctors may find themselves overwhelmed with requests of all sorts when no provision is made on what can (and cannot) be done. Juengst recognises this by claiming that even if the "therapy" extends to the improvement of the immune system, clear regulations can prevent stretching clinicians' roles and commitment to other illegitimate forms of enhancement.[130] Furthermore, it is also necessary to limit the already constrained resources of health care providers in allocating the relevant funding; and for the insurance companies to know what is to be covered and what is not.[131]

Nevertheless, it must be made clear that whilst this thesis focuses on the preventive intervention or health-related use of HGE, I do not contend that there are clear ethical justifications to use any applications of HGE merely because its applications fall under such categories. This thesis aims to further examine the current suggestion that HGE should only be used in relation to "serious genetic diseases". While NAS in its recent report does clarify "serious" monogenic disease to mean 'one that causes severe morbidity or premature death',[132] more clarity is needed. In particular, a solid theoretical framework is necessary to justify and guide policy making in this context of HGE, considering that there will be an expanding list of genetic disorders following the developments of genetic knowledge and genetic technologies (more detail in Chapter 4).

1.3.3 A child-centred approach: Different categories of children

When HGE is deemed safe and effective for human reproduction in the future, it will inevitably involve the implantation of the genetically modified embryo into a woman's womb with subsequent pregnancy and birth of an individual with the modified genes. From this, three possible categories of "children" can be identified, all of which should be taken into account in the ethical and regulatory discussion about HGE. These include (1) the unborn children (those who are conceived but not yet born, i.e. the embryos or foetuses); (2) the prospective children born as a result

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[130] Supra note 5, Juengst (1997).

[131] Supra note 97, Morrison (2015) 17; see also Eric Juengst, 'What Does Enhancement Mean?' in Erik Parens (ed), *Enhancing Human Traits: Ethical and Social Implications* (Washington, DC: Georgetown University Press 1998) 29.

[132] Supra note 56, NAS (2020).

of the procedure, or sometimes referred to as the immediate future children; and (3) the hypothetical distant future children (descendants who may or may not exist in the future). As I show in this section, each category raises its very own ethical (and legal) issues; thus, it is useful to clarify this at the outset of this thesis.

It is also worth noting that there are times where the interests of each category of "children" may coincide with one another. For instance, when considering whether it is ethically permissible to genetically modify the human gametes, i.e. the sperms or eggs, and human embryos for reproductive purposes, we unavoidably also consider, among other things, the potential benefits and risks of such procedure to the resulting children. Furthermore, the "rights" or interests conferred on one category of "children" may conflict with those in another category. For instance, those who hold a conservative view towards all kinds of human embryonic research may oppose genome editing on the embryos due to their view on the moral status of embryos.[133] This view conflicts with those who claim that children should enjoy, inter alia, the right to scientific research which, if successfully established, would imply an ethically acceptable clinical use of HGE on the ground that the prospective children can enjoy the potential benefits derived from the procedure.[134] With these in mind, it is essential to make clear what is and what is not covered in this thesis to avoid unnecessary confusion on the arguments made. In the following, I outline some of the common issues arising in each category of "children" and clarify which of them are the focus of this thesis.

- *The unborn children*

In the first scenario involving the unborn children, a typical question is whether it is ethically justified to generate numerous human embryos for experimental procedure or scientific research (including HGE). This relates to the moral status of human

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[133] Dana Carroll and R Alta Charo, 'The Societal Opportunities and Challenges of Genome Editing' (2015) 16 Genome Biology 242, 6.

[134] See for instance, Bartha Maria Knoppers and Erika Kleiderman, 'Heritable Genome Editing: Who Speaks for ''Future'' Children?' (2019) 2 The CRISPR Journal 285, 287. (Note: One can understand this difference by the different ethical perspectives, that is one from an ontological view of human embryos and the other from a consequentialist view of human embryonic research. For a discussion of how these different perspectives come into play in a biotechnology context, see for instance Andrew Siegel, 'Ethics of Stem Cell Research' (Stanford Encyclopaedia of Philosophy 2018) <https://plato.stanford.edu/entries/stem-cells/> accessed 03 August 2021.)

embryos and/or an 'alleged right to life to the unborn'[135] given that some of the embryos will be discarded after the research.[136] This thesis will not discuss the moral or legal status of the unborn children (i.e. the embryos and foetuses) because such issues are not unique to the debate of HGE: it is common to many other contexts relating to reproduction, including abortion[137] and other assisted reproductive technologies.[138] While this topic remains controversial in academia, this thesis follows the decision by the European Court of Human Rights in *Evans v United Kingdom*[139] – a case involving female and male reproductive rights over conflicts on the use of frozen embryos – where the Court affirmed that under English law, an embryo is not legally recognised to have independent rights or interests. Accordingly, the arguments from this thesis work from the assumption that it is ethically acceptable to conduct scientific procedure such as HGE on human embryos (and gametes). Instead of questioning the legal or moral status of the unborn children, this thesis draws closer attention to an identity-based perspective when considering the ethical and legal implications of genetically modifying human embryos and gametes (see further Chapter 5).

- *The prospective children*

In the second scenario involving the resulting children, attention is on the immediate future children who will actually be born because of the HGE procedure (with successful implantation of genetically modified embryos into a woman's womb). In this instance, the "best interests" of children is often the primary consideration. Before going into what is covered in this thesis in this regard, it is important to first

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[135] Stephen P Marks, 'Tying Prometheus Down: The International Law of Human Genetic Manipulation' (2002) 3 Chicago Journal of International Law 115, 131. Marks sees this claim as a potential argument raised by the opponents of genome manipulation although he admits that the current international interpretations on children's human rights do not support this stance.

[136] See for instance, Niklaus H Evitt, Shamik Mascharak and Russ B Altman, 'Human Germline CRISPR-Cas Modification: Toward a Regulatory Framework' (2015) 15 The American Journal of Bioethics 25, 26. The authors adopt 'an intermediate moral status between nonhuman life and a foetus'. Consequently, they urge that the destruction of human embryos should be kept to the minimum.

[137] See for instance, Barbara Hewson, 'Reproductive Autonomy and the Ethics of Abortion' (2001) 27 Journal of Medical Ethics ii10.

[138] See for instance, Suzanne Wymelenberg, 'New Technologies: The Ethical and Social Issues' in *Science and Babies: Private Decisions, Public Dilemmas* (National Academy of Sciences 1990).

[139] *Evans v United Kingdom* (2007) Application No 6339/05.

clarify the use of the terms "best interests" and "welfare" of the child in the legal (and ethical) setting since they are frequently used interchangeably in areas involving children.[140]

The term "best interests" is used in the most influential international convention relating to children – the United Nations Convention on the Rights of the Child ("UNCRC"). Article 3 of the UNCRC provides that in making decisions concerning children, 'the best interests of the child shall be a primary consideration'. As the United Nations Committee ("UN Committee") explains, the concept of the child's best interests has three roles: first, it can be a substantive right in which a child has the right to have his/her best interests evaluated when it comes to decisions relating to the child; second, it acts as an interpretative legal principle in which the interpretation of certain legal rules which 'most effectively serves the child's best interests' should be favoured; and third, it is a rule of procedure where the relevant decision making process should include consideration of the child's best interests and weighing those interests with others' interests.[141] The best interests of the child should be weighed and decided in a way that the child can have 'full and effective enjoyment' of the rights provided in the UNCRC and by considering the 'holistic development'[142] of the child.[143] Accordingly, the concept of best interests as intended by the UNCRC is extensive enough to cover a broad range of aspects concerning the child.

Instead of "best interests", the UK legislation governing matters relating to children adopts the word "welfare". For instance, Section 1 of the Children Act 1989 provides that the child's 'welfare shall be the court's paramount consideration' in proceedings concerning the upbringing of the child (or the administration of the

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[140] A point highlighted by the authors in Helen Stalford and Kathryn Hollingsworth, 'Judging Children's Rights: Tendencies, Tensions, Constraints and Opportunities' in Helen Stalford and Others (eds), *Rewriting Children's Rights Judgments* (Hart Publishing 2017) 34.

[141] UN Committee on the Rights of the Child (CRC), 'General Comment No. 14 on the Rights of the Child to Have His or Her Best Interests Taken as a Primary Consideration (Art 3, Para 1)' (29 May 2013) UN Doc CRC/C/GC/14, para 6.

[142] UN Committee on the Rights of the Child (CRC), 'General Comment No. 5: General Measures of Implementation of the Convention on the Rights of the Child (Arts. 4, 42 and 44, para. 6)' (27 November 2003) UN Doc CRC/GC/2003/5, para 12. The UN Committee explicitly advises nations 'to interpret "development" in its broadest sense as a holistic concept, embracing the child's physical, mental, spiritual, moral, psychological and social development' (albeit in the context of Art 6 which provides for the child's right to survival and development).

[143] Supra note 141, CRC (2013) paras 4 & 82.

child's property). Section 1(3) sets out several factors that the court must take into consideration, including the child's 'physical, emotional and educational needs' and 'the likely effect on him of any change in his circumstances'. This indicates that, as the concept of the best interests enshrined in the UNCRC, the welfare principle under the Children Act 1989 also covers the well-being of the child quite broadly in the sense that it covers not only the physical well-being but also psychological and psychosocial well-being of the child.[144]

The concept of welfare has also been used in the legislation on assisted reproductive technologies. Section 13(5) of the Human Fertilisation and Embryology Act 1990 (as amended in 2008) provides that in infertility treatment, licensed clinics should take into account 'the welfare of a child who may be born as a result of the treatment' and this explicitly includes 'the need of that child for supportive parenting'. Supportive parenting is further defined as 'a commitment to the health, well-being and development of the child'.[145] Here, it implies that the notion of "welfare" may be much wider than "well-being".[146] More importantly, although the highlighted clinical use of HGE in this thesis may not deal with infertility and the application of the "welfare principle" in the use of infertility treatment is itself subject to

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[144] There are different weights placed when judging the interests of children based on the UNCRC and the Children Act 1989. The latter which provides that the child's welfare should be *the* paramount consideration suggests that children's welfare outweighs all other interests at stake. For a critique on the paramountcy principle implied by the child's welfare principle in Children Act 1989, see for instance, Helen Reece, 'The Paramountcy Principle: Consensus or Construct?' (1996) 49 Current Legal Problems 267. Nonetheless, it is worth noting that there may be scope for interpreting 'welfare' more in line with the best interests enshrined in the UNCRC. For instance, Lady Hale observed that the UK law (e.g. as in section 1(1) of the Children Act 1989) is inspired by its international obligations under UNCRC (In *re E (Children) (Abduction: Custody Appeal)* [2011] UKSC 27 at para 12) and that section 11 of the Children Act 2004 which places a duty upon public authorities to perform their functions with respect to the need to safeguard and promote the welfare of children has captured 'the spirit, if not the precise language' of Article 3(1) of the UNCRC (see *ZH (Tanzania) v SSHD* [2011] UKSC 4; [2011] 1 WLR 148 at para 23).

[145] Supra note 129, HFEA (2017) para 8.11; see also, HFEA, 'Tomorrow's Children: Report of the Policy Review of Welfare of the Child Assessments in Licensed Assisted Conception Clinics' (November 2005) <https://www.yumpu.com/en/document/read/29594901/tomorrows-children-human-fertilisation-and-embryology-authority> accessed 29 December 2020 where the HFEA advises the clinics to consider 'medical, physical or psychological harm' of the child to be born due to the treatment.

[146] In its report concerning HGE, Nuffield Council on Bioethics ("Nuffield") explains its preference for the word 'welfare' over 'well-being' because the concept of welfare is wider than that of well-being and that welfare indicates 'doing well' while the latter indicates 'being well'. This means that, in Nuffield's terms, 'welfare' could cover not only physical good health but also psychosocial well-being. See Nuffield Council on Bioethics, *Genome Editing and Human Reproduction: Social and Ethical Issues* (Nuffield Council on Bioethics 2018) para 3.46.

controversy,[147] the incorporation of this principle in preconception cases by the legislators conveys the message that future possible children's interests do matter.

Acknowledging that these terms connote different interpretations and application standards particularly in the judicial context,[148] this thesis will not argue on the technical distinction between these terms. This thesis also does not debate the practicality of the concept of best interests and welfare principle in contexts relating to children and reproduction. Rather, in line with a child-centred approach, this thesis employs 'a more holistic appraisal of the best possible outcome for the (prospective) children'[149] born as a result of HGE. Thus, what is central to this thesis is not merely the possible physical (health) outcome that may be attained by the use of HGE but also the potential psychosocial and psychological impacts on the resulting children derived from either (1) the use of such procedure as a means of conception, (2) the unforeseen side effects from the procedure, or (3) having to live with certain hereditary diseases without resorting to the procedure. With this in mind, this thesis adopts a capability approach together with an identity-based model. This thesis shall consider how this framework may effectively address the interests of children in a holistic way and provide a comprehensive understanding of the overall welfare of the resulting children in the context of HGE (see Chapters 4, 5 and 6).

While the discussion so far may appear individualistic in the sense that it considers the interests of the prospective children as distinct individuals, it is important to note that children can also be considered as a group, giving rise to collective interests. In a similar vein, the UN Committee highlights that not only can the child's best interests be seen as an individual right, but also a collective right.[150] In making collective decisions concerning children, the regulators must evaluate and determine the best interests of children in view of the relevant contexts of the particular group

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[147] See for instance, Emily Jackson, 'Conception and the Irrelevance of the Welfare Principle' (2002) 65 The Modern Law Review 176; Sacha Rebecca Waxman, 'The Pre-Conception Welfare Principle: A Case Against Regulation' (PhD Thesis, University of Manchester 2017), Chapter 6 where the author argues that the preconception welfare principle in assisted reproductive technologies is indefensible because it is conceptually unclear.

[148] Supra note 140, Stalford and Hollingsworth (2017) 35-36 where the authors emphasise that the conflated use of these terms may cause confusion in the sense of mixing up the different thresholds each supposedly represents.

[149] Ibid, 36-37.

[150] Supra note 141, CRC (2013) para 23.

(or in general).[151] In the HGE debate, the interests of children can (and should) be addressed both individually and collectively. As I demonstrate later in Chapters 3, 5 and 6, an identity-based approach is able to shed light on how the "identity" interests of children are relevant to them both as an individual and/or as a group.

- The distant future children

In the third scenario involving the hypothetical future children, future generations must be considered as a whole. Since HGE will bring heritable effects not only to the resulting children but also the children's descendants, the ethical and regulatory debate must take into account the assumed benefits and potential adverse effects derived from the procedure to the (distant) future generations.[152] "Future generations" here means the remote possible future generations – those who are not yet conceived and born but may (or may not) exist in the distant future. In light of this category of "children", Baylis and Robert encourage us to consider the multigenerational impacts with the possible widespread use of germline editing (be it for disease or non-disease purposes) in the future.[153]

There is a need to distinguish this category (remote future children) from the second scenario discussed earlier which includes the immediate future children because there may be different concepts and/or ethics that apply to each category. For instance, the concept of intergenerational justice or intergenerational ethics is more relevant to discuss obligations from the present generations to remote future generations.[154] Intergenerational justice generally looks at the relevant notions of distributive justice in addressing any intergenerational conflict of interests and whether the present generations may be required to abandon those policies that may

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[151] Ibid.

[152] See for instance, Christoph Rehmann-Sutter, 'Why Human Germline Editing is More Problematic than Selecting Between Embryos: Ethically Considering Intergenerational Relationships' (2018) 24 The New Bioethics 9.

[153] Francoise Baylis and Jason Scott Robert, 'Radical Rupture: Exploring Biological Sequelae of Volitional Inheritable Genetic Modification' in John Rasko, Gabrielle O'Sullivan, and Rachel Ankeny (eds), *The Ethics of Inheritable Genetic Modification: A Dividing Line?* (Cambridge University Press 2006) 131-148. Baylis and Robert introduce the notion of 'radical rupture' and explain how heritable genetic modification could affect our 'genetic inheritance, genetic history and legacy, and interspecific engineering and speciation'.

[154] See for instance, Len Doyal and Sheila McLean, 'Choosing Children: Intergenerational Justice?' (2005) 10 Supp 1 Reproductive Biomedicine Online 119; also, Lawrence B Solum, 'To Our Children's Children's Children: The Problems of Intergenerational Ethics' (2001) 35 Loyola of Los Angeles Law Review 163.

inflict an intergenerational distribution of costs and benefits with an unjust outcome.[155] This thesis will not explore intergenerational justice; hence the questions of whether (and in what form) there can be a legal or moral obligation from the present generations to the distant future generations[156] and how this would affect the eventual employment of HGE in reproduction are beyond the remit of this thesis.

As suggested earlier, I am taking an identity-based model in this thesis when considering the “future children” (both immediate and remote). One common concern raised in the area of reproduction is the existence and non-existence of future people due to our specific reproductive choices (see further Chapter 3). This thesis examines how “identity” is relevant in this regard and its ethico-legal implications in the HGE debate. Furthermore, as HGE involves the intentional alteration of genetic makeup of individuals before birth and any modified genes will be inherited, it also raises the concern whether there is (or should be) a kind of “identity” preserved for future people. I also explore this concern in this thesis (Chapter 3).

In brief, the overall research of this project is limited to an examination of the ethico-legal issues surrounding heritable genome editing of the nuclear genome (“HGE”). This thesis focuses on the possible use of HGE for the prevention of transmission of genetic diseases (so-called “health-related purpose” or “preventive intervention”), hence excluding thorough discussions on the socio-ethical and legal issues of human enhancement. Most importantly, this thesis adopts a child-centred approach in the discussion which directs more attention to “children” in the context of HGE (“children” is understood in this thesis as having the status of the offspring of their parents, not just merely individuals below the age of maturity). As it is now clear the scope of this thesis, I continue by detailing my research methodology.

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[155] For an overview of intergenerational justice, see Lukas Meyer, ‘Intergenerational Justice’ (Stanford Encyclopaedia of Philosophy 2015) <https://plato.stanford.edu/entries/justice-intergenerational/> accessed 29 December 2020.

[156] For a detailed understanding of intergenerational justice from a philosophical perspective, see Axel P Grosseries, ‘What Do We Owe the Next Generation(s)’ (2001) 35 Loyola of Los Angeles Law Review 293.

1.4 Research Methodology

Before outlining the overall structure of this thesis, it is worth clarifying that the research in this thesis is conducted by using the methods below.

(a) **Traditional literature review**: The thesis carries out critical analysis using the traditional or narrative literature review. This type of review, in contrast to a systematic literature review,[157] helps to identify and review published literature, including official reports and policy documents, on a topic. It usually employs a narrative approach to present the review findings.[158] This method is important to identify the knowledge gaps by having a picture of what has already been achieved in the current field, to provide arguments and recommendations building upon previous work and to avoid unnecessary repetition.[159] This is a crucial method for my research. In order to have a substantial understanding of the current ethico-legal debate on HGE, this thesis, in addition to peer-reviewed articles, also explores some of the major official publications on human genome editing, including those by the then President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioural; Nuffield Council on Bioethics; and National Academies of Sciences, Engineering, and Medicine. These official publications provide useful discussion on some of the important issues associated with genome editing technologies (including HGE) and are referred throughout this thesis. Moreover, the official reports by the Human Fertilisation and Embryology Authority and the UK Department of Health, particularly those relating to MRT are also analysed, to consider how the legalisation of the procedure has been made in the UK and what lessons can be learned for HGE. Other literature including those related to children's rights and unborn children (or future individuals) are also explored to understand the state of art and to identify the lacunae in existing research.

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[157] This can be understood as 'a systematic, explicit, comprehensive, and reproducible method for identifying, evaluating, and synthesizing the existing body of completed and recorded work produced by researchers, scholars, and practitioners'. See Chitu Okoli and Kira Schabram, 'A Guide to Conducting a Systematic Literature Review of Information Systems Research' (2010) 10 Sprouts: Working Papers on Information Systems 1, 4.

[158] Charles Sturt University Library, 'Literature Review: Types of Literature Reviews' (2020) <https://libguides.csu.edu.au/review/Types> accessed 29 December 2020.

[159] Maria Grant and Andrew Booth, 'A Typology of Reviews: An Analysis of 14 Review Types and Associated Methodologies' (2009) 26 Health Information and Libraries Journal 91.

(b) **Doctrinal and socio-legal research**: The doctrinal research draws on the analysis of legal texts, fundamentally dealing with the question of 'what is the law?' in a particular context.[160] This method consists of two steps: first, identifying the primary sources of the law and second, evaluating the text so as to establish the nature and substance of the law.[161] This method is used in this thesis to analyse, for instance, the law of wrongful life in the UK, the international provisions concerning human genome editing such as the Universal Declaration on the Human Genome and Human Rights 1997 and the Oviedo Convention 1997 (see Chapter 3); and the law, including local and the European human rights cases, on the right to know for children (see Chapter 6). It must be noted that the doctrinal analysis carried out here cannot be well-explained without taking into account the historical or societal context of the law. Hence, a socio-legal approach which stresses a sociological understanding of law[162] is also adopted. Particularly regarding to a right to know in Chapter 6, this thesis also considers how the relevant law is heavily influenced by the social context, for instance, the claim for a right to know in the context of gamete donation has only been minimal in the 1900s due to the dismissive attitude towards artificial reproduction and infertility. This observation is important for the current debate of HGE for it implies that the claim for a right to know may also be influenced by the societal attitude on the employment of this technology.

(c) **Interdisciplinary approach**: An interdisciplinary research involves sharing and merging perspectives from different disciplines.[163] The issues associated with HGE are wide-ranging and complex; hence, the debate has always involved a broad range of stakeholders including scientists, bioethicists, lawyers, philosophers, disabilities rights advocates,[164] to which an interdisciplinary conversation fits well in the

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[160] Paul Chynoweth, 'Legal research' in Andrew Knight and Les Ruddock (eds), *Advanced Research Methods in the Built Environment* (Wiley-Balckwell 2008), 29-30; Salim Ibrahim Ali and Others, 'Legal Research of Doctrinal and Non-Doctrinal' 4 International Journal of Trend in Research and Development 493, 493.

[161] Terry Hutchinson and Nigel James Duncan, 'Defining and Describing What We Do: Doctrinal Legal Research' (2012) 17 Deakin Law Review 83, 110.

[162] David Schiff, 'Socio-Legal Theory: Social Structure and Law' (1976) 39 The Modern Law Review 287, 287; Roger Cotterrell, 'Why Must Legal Ideas be Interpreted Sociologically?' (1998) 25 Journal of Law and Society 171.

[163] David Robertson, Douglas Martin and Peter Singer, 'Interdisciplinary Research: Putting the Methods under the Microscope' (2003) 3 BMC Medical Research Methodology 20, 21.

[164] See for instance, Lluis Montoliu and Others, 'ARRIGE Arrives: Toward the Responsible Use of Genome Editing' (2018) 1 The CRISPR Journal 128. A new non-profit organisation called ARRIGE is set up in March 2018 to promote an

context. This thesis sees the interdisciplinary approach as inevitable in carrying out the analysis; it looks into the literature not only from law but also philosophy, science, ethics, psychology and social science. Apart from the fact that the ethical issues of the application of HGE cannot be well-explained by focusing only on a single perspective, an interdisciplinary approach is particularly useful in my research to understand different interpretations of a theory or concept applied in various fields. An example would be the concept of "identity" in which it has been interpreted differently in the field of philosophy, law, and social science (see Chapter 5).

All these methods identified here complement each other in order to facilitate better understanding of the debate concerning HGE and provide coherent answers to the research questions of this thesis.

1.5 Structure of This Thesis

This chapter concludes with an overview of the overall structure of the thesis. There are seven chapters in this thesis. Each of the chapters is outlined as follows.

The current chapter, **Chapter 1**, provides an overview of the genome editing technologies, particularly HGE. It provides a scientific background of this procedure and highlights both the prospects and controversies in employing the technology for reproductive purposes. Drawing upon this discussion, it also identifies the motivations and aims for this thesis. It then presents the research questions and the scope within and beyond the thesis in answering these questions. After briefly explaining the research methodology for this thesis, this chapter ends with an outline of the whole thesis.

Chapter 2 is a contextual chapter which highlights two major controversies surrounding the application of genetic knowledge in human reproduction. First, it examines the nature and extent of parental reproductive freedom and its relevance in relation to the use of HGE in reproduction. Second, it examines the "eugenics" concern in the context of HGE. These issues, though they do not form part of my thesis arguments, must be considered in any debate relating to the use of genetic

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inclusive debate by setting up a platform for people from different disciplines to address issues raised by genome editing technologies.

technologies in reproductive settings. Hence, it is essential that this chapter sets out my positioning in relation to these issues before I make any other substantial arguments.

Chapter 3 examines the position of “children” in the current HGE debate. In particular, it explores four child-centric arguments: (1) Derek Parfit’s non-identity problem; (2) Joel Feinberg’s right to an open future; (3) the purported right to a genuine “genetic identity”; and (4) the proposed long-term monitoring mechanism. The purpose of this analysis is to identify the gaps in the existing discussion by examining whether the interests of children are appropriately considered and safeguarded through these approaches. This chapter argues that the present arguments fail to constructively protect the (future) children’s interests for two main reasons. First, concerning the commonly made suggestion on the use of HGE for health-related purposes, there is a lack of an adequate theoretical framework to justify such a purpose and to constrain its use (“1st Gap”). This observation deserves careful attention for it risks “health” taken as a convenient bridge to justify controversial technique such as HGE and whatever consequences, it is the resultant children who have to live with it. Second, there is also a lack of robust analysis of the concept of “identity” (“2nd Gap”). This observation is also problematic as it renders the whole debate on HGE incomplete and sometimes confusing.

Chapter 4 addresses the 1st Gap identified in Chapter 3. Specifically, it draws on the capability approach, associated with Amartya Sen and Martha Nussbaum. Since this thesis concerns the preventive intervention or health-related purposes of HGE, it also explores Jennifer Ruger’s health capability approach. This chapter argues that a capability approach provides insights that can appropriately consider and safeguard the interests of future children. Furthermore, it demonstrates how the capability approach perspective can provide a theoretical and normative framework to justify the current recommendations to only allow HGE for health-related purposes and to further limit its use within the health-related grounds.

Chapter 5 addresses the 2nd Gap identified in Chapter 3. It provides a comprehensive analysis of the different interpretations of “identity”. Particularly, it explores the applicability of “genetic identity”, “numerical identity”, “qualitative identity” and “narrative identity” in the genetic context. It then examines the utility of these various types of “identity” in answering the ethical permissibility and the eventual regulations of HGE, with “children” considered. It argues that what is needed is a multi-faceted notion of identity and that this can render the overall debate of HGE more nuanced and dynamic.

Chapter 6 further elaborates on the issue of how “genetic identity” is interpreted in the legal and policy realm. Specifically, it examines this issue in light of a right to know. This discussion is important because it demonstrates how closely such an interpretation of “genetic identity” is related to one’s (narrative) identity. **Part I** of this chapter focuses on the conceptual basis for a right to know currently made for children in the context of adoption, donor conception and paternity proceedings from the international and UK perspective. It also points out how a right to know has been interpreted quite differently in the context of MRT in the UK and what lessons can be drawn from this setting for the HGE context. **Part II** of this chapter defends a claim for a right to know for the prospective children born through HGE. In particular, it explains the connection between “capabilities” and “identity”. Drawing from such insights, the chapter delineates what a right to know means in the context of HGE, what should the right entail, and how could it be enforced.

Chapter 7 is the concluding chapter in which it summarises the overall arguments of the whole thesis along with the original contributions that has been made and further provides the areas for future research.

Chapter 2 – Genetics and Reproduction: Some Fundamental Ethical Viewpoints

The application of genome editing in human reproduction is highly contentious. As shown in Chapter 1, although this technology generates new hope, it simultaneously creates much fear. The idea of a 'genetic supermarket' where it is imagined that prospective parents could 'shop for' desired traits for their future children[165] leads us to envisage an increasing ability given to parents in controlling the nature of their children. This raises the question of how much control or freedom parents have (or should have) in this regard. This issue closely relates to more specific questions such as the (possibly, new) obligations of parents towards their children regarding the availability of human heritable genome editing ("HGE") in the near future and how the government should provide and regulate such access.[166] While the restriction on individuals' reproductive rights imposed by the governments or other regulatory bodies may go wrong, as part of the historical eugenic events remind us, unrestrictive freedom on reproductive matters similarly rings the eugenic bells, albeit in a new form. This chapter briefly comments on these controversies which are based on a parent-centred approach and society-centred approach. Although this thesis does not consider the ethico-legal issues of HGE from such approaches, these issues deserve careful attention as they inevitably also relate to children's interests, the focus of this thesis.

This chapter first elaborates on the notion of reproductive freedom, followed by a discussion on eugenics. For each of the discussion, I state my positioning, respectively, on the following issues – first, whether (and, to what extent) the use of HGE should be protected under the notion of reproductive freedom; second, the relevance and significance of the eugenic concerns in the context of HGE. In particular, the arguments made later in this thesis are oriented in the two positions identified in this chapter: (1) when rights are conceptualised as non-absolute, there

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[165] Robert Nozick first introduces such a notion. See Robert Nozick, *Anarchy, State, and Utopia* (Basic Books 1974) 315 where Nozick suggests that in the genetic supermarket, there is 'no centralised decision' by the state in deciding the type of future people but instead decisions are left in the hands of prospective parents; also see Colin Gavaghan, *Defending the Genetic Supermarket: The Law and Ethics of Selecting the Next Generation* (Routledge Cavendish 2007).

[166] Chris Gyngell and Thomas Douglas, 'Stocking the Genetic Supermarket: Reproductive Genetic Technologies and Collective Action Problems' (2015) 29 Bioethics 241, 241-242.

can be legitimate reasons to justify curtailing such rights (e.g. parents' reproductive rights can be justifiably restricted on the grounds of protecting (future) children's interests); and (2) as for the eugenic concerns which relate closely to the exercise of parental rights in the use of genetic technology including HGE, I acknowledge that HGE, even proposed for health-related purposes, may in principle be identified as a form of "eugenics". However, the label itself does not necessarily mean that any use of HGE is ethically unjustifiable.

2.1 Reproductive Freedom in the Context of Heritable Genome Editing

With the rapid development in science and genetic technologies, it is suggested that it is merely a matter of time until HGE is eventually introduced as part of assisted reproductive technology services for prospective parents.[167] It follows that there arises the concern of how much control (or freedom) parents can have over their prospective children's genes prior to birth. This is often discussed with a parent-centred approach by appealing to the concept of reproductive autonomy, which, in its simplest form, connotes recognising the freedom of individuals in making the decision either to reproduce or not to reproduce.[168] Reproductive autonomy is sometimes also referred to as reproductive freedom,[169] reproductive liberty,[170] procreative autonomy[171] or procreative liberty.[172] This thesis uses these phrases interchangeably to carry the same meaning unless otherwise stated, noting that

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[167] Jamie Metzl, *Hacking Darwin: Genetic Engineering and the Future of Humanity* (Sourcebooks 2019); Francoise Baylis, *Altered Inheritance: CRISPR and the Ethics of Human Genome Editing* (Harvard University Press 2019).

[168] See for instance, Erin Nelson, *Law, Policy and Reproductive Autonomy* (Hart Publishing London 2013).

[169] For instance, see Timothy Zick, 'Re-Defining Reproductive Freedom' (1998) 21 Harvard Women's Law Journal 327, where the author uses the terms 'reproductive autonomy' and 'reproductive freedom' interchangeably.

[170] For instance, in Robert Sparrow, 'Therapeutic Cloning and Reproductive Liberty' (2009) 34 The Journal of Medicine and Philosophy 102, the author adopts the phrase 'reproductive liberty' in suggesting that decisions about reproduction should be given to the prospective parents.

[171] See for instance, Tom Buller and Stephanie Bauer, 'Balancing Procreative Autonomy and Parental Responsibility' (2011) 20 Cambridge Quarterly of Healthcare Ethics 268.

[172] See for instance, John Robertson, *Children of Choice: Freedom and the New Reproductive Technologies* (Princeton University Press 1994).

there may be some differences in the emphasis on the scope and impact of these terms.[173]

In this section, I first explore the nature and extent of reproductive freedom and its moral importance. I highlight two controversial components of reproductive freedom most relevant to the context of HGE: first, the choice of determining what kind of children to have and second, the choice of having a genetically related child. I argue that, given the moral bases of the value of reproductive freedom, parental decisions in reproductive matters, including decisions in regard to HGE, should be respected, unless it is proven that it will bring significant harm to others, such as future children. This claim is not inconsistent with a child-centred approach in that parental exercise of their rights including those in reproductive matters need not necessarily be in conflict with children's rights and/or interests.

2.1.1 The nature, value and extent of reproductive freedom

The concept of reproductive freedom has a role in ethical discourses with special normative relevance to acts falling within the scope of such freedom,[174] although defining its scope is not without dispute. What is commonly agreed is the position that 'if an act falls within the scope of reproductive freedom, a legitimate regulation or prohibition of this act by state authority must meet a particularly high level of justification'.[175] By demanding that there must be good reasons before intervening in individuals' reproductive freedom, it is clear that such freedom (as with many other kinds of freedom given in a democratic society such as freedom of speech), though highly valuable for the reasons discussed shortly, is of a non-absolute

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[173] Johnston and Zacharias, for instance, observe that the term 'procreative liberty', famously used by John Robertson, is an extension of 'reproductive freedom' where 'procreative liberty' is used to capture the freedom to reproduce via assisted reproductive technologies, thereby suggesting that procreative liberty falls under the umbrella of reproductive freedom. See Josephine Johnston and Rachel Zacharias, 'The Future of Reproductive Autonomy' (2017) 47 Hastings Center Report S6, S9; also Laura Shauuer, 'The Right to Procreate: When Rights Claims Have Gone Wrong' (1995) 40 McGill Law Journal 823, 826 where the author suggests that 'reproductive rights' are broader than 'procreative rights' – the latter are rights to have children or not while the former also covers the timing and method in which one reproduces. It is beyond the remit of this thesis to explore the possible differences between these terms.

[174] Dustin GooBens, 'The Use of Human Artificial Gametes and the Limits of Reproductive Freedom' (2021) 35 Bioethics 72, 73.

[175] Ibid, 72-73.

nature.[176] Reproductive freedom is also legal recognised. Of particular importance is Article 8 of the European Convention on Human Rights ("ECHR"). Article 8 provides for a right to respect for family and private life including matters relating to reproduction such as the decision whether or not to become a parent.[177] Article 8(2) first appears to have indicated that such a right is a negative one in which a public authority should not interfere, unless the intervention falls within the grounds provided.[178]

Harris' statement that 'the key idea of reproductive liberty is surely respect for autonomy and for the values which underline the importance attached to procreation' captures at least two moral bases to defend why reproductive freedom is valuable and ought to be respected.[179] "Respect for autonomy" grounding focuses on the centrality of reproductive decisions for the development of personal life plans and thus the morally relevant interest of individuals creating their own lives following the interests or values that they hold true to themselves.[180] Another moral basis for respecting reproductive freedom is due to the 'values which underline the importance attached to procreation'. This is often described as the "welfarist argument" where reproduction is seen as relevant to individuals' well-being[181] and is viewed as a 'core human activity' which has a significant impact on an individual's

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[176] Giulia Cavaliere, 'The Problem with Reproductive Freedom. Procreation Beyond Procreators' Interests' (2020) 23 Medicine, Health Care and Philosophy 131, 132.

[177] United Nations, 'Reproductive Rights Are Human Rights: A Handbook for National Human Rights Institutions' (2014) <https://www.ohchr.org/documents/publications/nhrihandbook.pdf> accessed 30 August 2021, 106-107.

[178] Article 8(2) provides non-interference on the right unless it is according to the law and is necessary for the interests of 'national security, public safety or the economic well-being of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others'.

[179] John Harris, *Enhancing evolution* (Princeton University Press 2007) 76.

[180] Allen Buchanan, Dan W Brock, Norman Daniels and Daniel Wikler, *From Chance to Choice: Genetics and Justice* (Cambridge University Press 2001) 214-215.

[181] Giulia Cavaliere and Cesar Palacios-Gonzalez, 'Lesbian Motherhood and Mitochondrial Replacement Techniques: Reproductive Freedom and Genetic Kinship' (2018) 44 Journal of Medical Ethics 835, 839; also Dan W Brock, 'Shaping Future Children: Parental Rights and Societal Interests' (2005) 13 The Journal of Political Philosophy 377, 382-383. Brock acknowledges three types of personal well-being in relation to procreation: (1) conscious experience theories which understand well-being as having positive conscious experience, like pleasure; (2) preference theories which understand well-being as satisfying one's preferences; and (3) objective list theories which understand well-being as being determined by a list of objectively good notions of human life.

identity, dignity and meaning of one's life.[182] Applied to the HGE debate, the autonomy and welfarist arguments, at the first instance, do provide a sound moral defence of the right of prospective parents at risk of transmitting certain genetic conditions to their children to reproduce as they want and to have healthy children that are genetically related to both of them. Constraining or failing to respect reproductive freedom is thought to adversely impact individuals' well-being and their ability to shape a good life.[183] Given the significant impact that reproduction can have on one's life, Robertson argues that procreative liberty should have the 'presumptive primacy', meaning that this form of liberty should be presumed to have priority when there are conflicts with its exercise. Also, Gavaghan argues 'we should assume that all reproductive decisions are important to people making them; whether the decision involves (…) electing to have a child with particular traits and it should not be incumbent on anyone to prove how much these decisions matter to them'.[184]

How far reproductive freedom should extend, especially in light of the increasing use of assisted reproductive technology, remains a constant debate. Besides debating the negative (non-interference without justifiable grounds for the exercise of such freedom) and positive elements (focusing on providing access or assistance to individuals in reproductive matters) of reproductive freedom,[185] some commentators have raised several aspects of reproductive freedom as highly controversial. In particular, they question whether these aspects should be (equally) protected within

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[182] Supra note 172, Robertson (1994); John Harris, 'Rights and Reproductive Choice' in John Harris and Soren Holm (eds), *The Future of Human Reproduction: Ethics, Choice and Regulation* (Clarendon Press 1998) 35 where Harris claims that the freedom in decision making relating to reproduction is so similar to the freedom of religion that they protect the 'freedom to choose one's own way of life according to one's own most deeply held beliefs'.

[183] Supra note 181, Brock (2005).

[184] Supra note 165, Gavaghan (2007) 23.

[185] Reproductive freedom is initially more commonly defended as a negative right – that is, non-interference without justifiable grounds for the exercise of such liberty: supra note 173, Johnston and Zacharias (2017). Especially with the advance of assisted reproductive technology, there are increasing claims to defend reproductive freedom as a positive right, which focuses on providing access or assistance to individuals in reproductive matters. This line of thinking has received much academic attention. For instance, Catherine Mills argues that understanding reproductive autonomy as positive freedom is essential to respect the nature and significance of one's reproductive decisions: Catherine Mills, 'Reproductive Autonomy as Self-Making: Procreative Liberty and the Practice of Ethical Subjectivity' (2013) 38 Journal of Medicine and Philosophy 639, 655. Similarly, Emily Jackson argues that we should, as far as possible, provide assistance to those who cannot reproduce without medical aid so that they can exercise *meaningful* reproductive choice: Emily Jackson, 'In Defence of Reproductive Autonomy' in Volkmar Gessner and Professor David Nelken (eds), *Regulating Reproduction: Law, Technology and Autonomy* (Bloomsbury Publishing 2001) 1 & 162.

the umbrella of reproductive freedom. For instance, Brock argues that 'different aspects or components of reproductive freedom … will typically have different moral significance' and hence, 'it would be a mistake to think that the (reproductive) right is unitary in content or moral importance'.[186] In the following, I further explore two of these aspects which are controversial and the most relevant in the context of HGE: (1) the freedom to choose what types of children to have; and (2) the freedom of having genetically related children.

Genetic knowledge and technologies have vastly increased individuals' ability to identify the risks or presence of deleterious genetic conditions and to prevent them by refusing conception, or conceiving without the risk to the foetus (e.g. by using preimplantation genetic diagnosis "PGD" to screen the embryos and to select the one free from genetic conditions for implantation). Now with the prospects of CRISPR/Cas9, the scientists can even edit the genes of human gametes or early embryos so as to prevent the transmission of certain genetic diseases (and possibly in the future, to "enhance" physical/mental traits of the resulting children though whether, when and how this will become feasible remains unsettled and controversial as I pointed out in Chapter 1).[187] For the purpose of this thesis, I focus on the question of whether prospective parents should be allowed to use HGE with the aim to prevent the transmission of certain genetic diseases (or in other words, to have a healthy child).

HGE, as suggested in Chapter 1, could be a potential option for prospective parents to have healthy offspring who are genetically related to both parents.[188] This idea is not far-fetched considering that the mitochondrial replacement technique ("MRT")[189] has been developed and subsequently legalised in the UK 'within a framing of reproductive choice and disease prevention' as a possible technological solution for women suffering from mitochondrial disease who want to have a

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[186] Supra note 181, Brock (2005), 381.

[187] Ibid, 377.

[188] See for instance, supra note 146, Nuffield Council on Bioethics (2018) Chapter 1.

[189] As mentioned in Chapter 1, this technique involves donation of mitochondria of a third party to replace the unhealthy one.

genetically related, healthy child.[190] Thus, it is easily imagined that parents may claim that the use of HGE is essential for their reproductive goal in forming a family with genetically related *and* healthy children. Morally speaking, based on the reasons identified above, it can be assumed that the reproductive decision involving the use of HGE to have children free from certain genetic conditions should receive "presumptive primacy", unless there are good reasons to interfere with such decision (discussed below). However, it must be noted that whether the state has a positive obligation to help parents to ensure a healthy child remains disputable, as Robertson notes that reproductive rights are ordinarily rights against state intervention and not rights to obligate the state or private parties to provide access to certain services or resources if the provider decides not to provide.[191] This is well-illustrated in the case of *SH v Austria,*[192] which concerns Austrian regulations on artificial procreation, particularly in the area of gamete donation. In this case, two couples who needed donated sperm and ovum respectively for their in-vitro fertilisation (IVF) process claimed that there was a violation of Article 8 because Austrian law prohibits their access to IVF when donated gametes are involved (though the law does not prohibit the couples to travel overseas for such access).[193] The Grand Chamber of the European Court ruled that Article 8 guarantees 'the right of a couple to conceive a child and *to make use of* medically assisted procreation'[194] and affirmed that 'there may be positive obligations inherent in an effective respect for private and family life' under Article 8.[195] Nonetheless, though Article 8 was engaged, the Court eventually held that there had been no breach of Article 8 in this instance and upheld Austria's legal restrictions on certain assisted reproductive technologies on the basis that the issues (such as the use of donated gametes in IVF treatment) are socially and morally sensitive in the country and thus falling within Austrian government's

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[190] Supra note 34, Dimond and Stephens (2018) 5.

[191] John Robertson, 'Procreative Liberty and Harm to Offspring in Assisted Reproduction' (2004) 30 American Journal of Law & Medicine 7, 20.

[192] *SH v Austria*, App No 57813/00, ECtHR Judgment of 3 November 2011 [GC].

[193] Ibid, paras 11-15.

[194] Ibid, para 82 (italics are my emphasis).

[195] Ibid, para 87.

margin of appreciation.[196] This case demonstrates that while there is increasing recognition of the positive aspect of reproductive freedom in theory, there is still a gap in practice as to how it should be respected. From an international human rights perspective, this may be partly because the states are given a wide margin of appreciation in their regulations on assisted reproductive technologies which leads to inconsistent regulations in different countries.[197]

Next, in respect of the freedom to have a genetically related child, there is also controversy in regard to the moral importance of genetic relatedness and in particular, how much weight should be given to the parental decisions to have a genetically related child in the context of HGE. There are other existing alternatives to having genetically related and/or healthy children.[198] For instance, adoption and surrogacy are among the available alternatives to have healthy children; assisted reproductive technologies like gamete donation may ensure genetically related children to at least one parent; PGD may, in certain circumstances,[199] also offer the chance to have a genetically related and healthy child to parents who may otherwise inherit certain genetic conditions to the prospective child. However, I argue, considering the values of reproductive freedom discussed earlier, that the decision of parents to have children genetically related to both of them should, prima facie, be respected.

It is argued that the significance of genetic relatedness is reflected itself in the parental desire[200] to have children genetically related to them. This desire can be

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[196] Ibid, paras 94-97; 115-116. Note that the final judgment of this case has brought up much criticism on how the Court has failed to protect the human rights of infertile European individuals. See for instance, Wannes Van Hoof and Guido Pennings, ‘The Consequences of SH and Others v. Austria for Legislation on Gamete Donation: An Ethical Analysis of the European Court of Human Rights Judgments’ (2012) 25 Reproductive Biomedicine Online 665.

[197] Eyal Benvenisti, ‘Margin of Appreciation, Consensus, and Universal Standards’ (1999) 31 International Law and Politics 843, 844. The author observes that the doctrine of ‘margin of appreciation’ undermines the universality of human rights.

[198] Supra note 146, Nuffield Council on Bioethics (2018) 20-22.

[199] PGD will not be an option for a genetically related and healthy child in the circumstances such as the prospective parent is homozygous (having two similar alleles of a particular gene) for an autosomal-dominant disease or when both parents are homozygous for an autosomal-recessive disease. See for instance, Robert Ranisch, ‘Germline Genome Editing Versus Preimplantation Genetic Diagnosis: Is There A Case in Favour of Germline Interventions?’ (2019) Bioethics 1, 4.

[200] It is worth noting that the “desire” to have a genetically related child in general receives different view in regard to its weight among scholars. On one hand, for instance, Bredenoord and others view such desires as one important

seen in, for example, the use of in-vitro fertilisation (“IVF”) for infertile couples. Even when other parenting options such as adoption are available, they are willing to go through the IVF process, which is often costly, physically demanding and without guarantee that the embryos will be implanted successfully and result in pregnancy.[201] The prevalent use of genetic technologies in reproductive settings and the regulations in this field validate and recognise (at least, implicitly) the value of genetic relatedness. For instance, Danielle Griffiths observes, in the context of MRT, genetic relatedness has a significant place in this technique as it is to allow women to have healthy children with (mainly) their own genes.[202] Griffiths argues that having a genetically related child is deeply rooted in science and law in such context because the (legal) efforts are in place to realise this desire even though only a small amount of family (those who suffer the risk of inheriting mitochondrial diseases) may benefit from this technique.[203] Thus, it seems that the increasing legalisation of the use of assisted reproductive technologies, including the more controversial one such as MRT (controversial partly because it involves germline modification) has implicitly acknowledged the value of genetic relatedness as well. Additionally, increasing (legal) recognition to a right to know claim for the children to know their genetic parents in cases of gamete donation and paternity testing is also allegedly endorsing the value of genetic relatedness.[204] Yet, it is important to note that having a genetically related (and healthy) child is currently no way a legal right protected by law. In the UK, the Human Fertilisation and Embryology Authority grant licences for research, storage or fertility treatments involving gametes or embryos to the

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desire in many people’s lives and thus it is legitimate to help them fulfil such desires: Annelien Bredenoord and Others, ‘Ethics of Modifying the Mitochondrial Genome’ (2011) 37 Journal of Medical Ethics 97. On the other hand, some scholars, including Sparrow, argue that such desire should not be mistaken as reproductive interests (see Robert Sparrow, 'A Child's Right to a Decent Future? Regulating Human Genetic Enhancement in Multicultural Societies' (2012) 4 Asian Bioethics Review 355, 362; see also supra note 146, Nuffield Council on Bioethics (2018) para 3.7) because it hardly constitutes ‘rational preference’ or a ‘fundamental need’ (see Soren Holm, ‘The Need for Treatment’ in Donald Evans and Neil Pickering (eds), *Creating the Child: The Ethics, Law, and Practice of Assisted Procreation* (Martinus Nijhoff Publishers 1996) 73).

[201] Supra note 146, Nuffield Council on Bioethics (2018) para 3.4.

[202] Danielle Griffiths. ‘The (Re)Production of the Genetically Related Body in Law, Technology and Culture’ Mitochondria Replacement Therapy’ (2016) 24 Health Care Analysis 196, 205.

[203] Ibid. For instance, the clinical use of MRT has been legalised in the UK under the Human Fertilisation and Embryology (Mitochondrial Donation) Regulations 2015 after going through long process of public consultation.

[204] Kimberly Leighton, ‘To Criticise the Right to Know We Must Question the Value of Genetic Relatedness’ (2013) 13 The American Journal of Bioethics 54, 54.

researchers and clinics on a case-by-case basis, meaning that not every request of the prospective parents would be successful.[205]

In short, this section highlights the significant values of reproductive freedom. Following this, I maintain that the concept of reproductive freedom connotes the idea that parents should, in general, be allowed to make reproductive decisions including resorting to technologies for healthy and genetically related children unless there are ethically and legally acceptable grounds for interference by other parties.

2.1.2 The limitations of parental rights

As indicated earlier, it is implausible to consider parents as having an absolute power over their children. In Lord Fraser's words, 'parental rights to control a child do not exist for the benefit of the parents. They exist for the benefit of the child.'[206] Consequently, when there are harms likely to be imposed on children as a result of parental decisions, intervention by third parties can be reasonably applied. The limit or extent of parental rights is most precarious in the context of medical decisions involving minors when the courts are likely to intervene especially when the child's life is endangered by parental withholding of consent to certain medical treatment.[207] For instance, in the case of *Re S (a minor)(medical treatment),*[208] the court ordered that blood transfusions be given, as a necessary part of treatment for a four-year-old child who was suffering from T-cell leukaemia and whose parents refused to consent to the blood transfusion on religious basis. The court held that 'the test remained the welfare of the child as the paramount consideration'[209] and thus ordered the transfusions. Also, in *Re R (a minor) (blood transfusion),*[210] a 10-

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[205] Human Fertilisation and Embryology Authority, 'Statement on Mitochondrial Donation' <https://www.hfea.gov.uk/about-us/news-and-press-releases/2015-news-and-press-releases/statement-on-mitochondrial-donation/> accessed 29 December 2020; Human Fertilisation and Embryology Authority, 'Approved PGD and PTT Conditions' <https://www.hfea.gov.uk/treatments/embryo-testing-and-treatments-for-disease/approved-pgd-and-ptt-conditions/> accessed 29 December 2020.

[206] *Gillick v West Norfolk and Wisbech Area Health Authority and another* [1985] 3 All ER 402, 410, para c.

[207] Graeme Laurie, Shawn Harmon and Gerald Porter, *Mason and McCall Smith's Law and Medical Ethics* (10th edn, Oxford University Press 2016) 100, para 4.77.

[208] *Re S (a minor) (medical treatment)* [1993] 1 FLR 376.

[209] Ibid, 376.

[210] *Re R (a minor) (blood transfusion)* [1993] 2 FLR 757 (Fam).

month-old baby was suffering from B-cell lymphoblastic leukaemia. As part of the treatment, blood transfusions were needed. The parents who are Jehovah's Witnesses refused consent for any use of blood products. The court held that 'the child's need for blood was so overwhelming that for her welfare the parents' wishes had to be overridden and the use of blood products authorised'.[211] The court said, 'the welfare of the little girl is the court's paramount consideration… Without that treatment, the consensus is that the treatment will be unsuccessful, and she will suffer harm' and that it is 'in her best interests' to have the blood transfusions.[212]

Such cases demonstrate that the welfare of the child will always be the key consideration, and this is to be determined on the basis of what the courts deem to be the consequence of parental choices.[213] While these cases involve life-threatening conditions, there are also instances where the courts are ready to intervene in situations that do not involve imminently life-threatening illness yet there is clear scientific evidence that certain procedure will be beneficial for the children. This can be illustrated through the recent case of *Re H (a child) (parental responsibility: vaccination)*[214] in which the issue of whether local authority can exercise its statutory power to authorise vaccination in face of the objections of parents was involved. The Court of Appeal held that even though vaccinations are not mandatory, it is clear that there is scientific evidence which establishes that 'it is in the best medical interests' of children to be vaccinated. The Court also held that parental views concerning vaccination must always be considered but the weight given should be upon their substance because 'the view has a real bearing on the child's welfare'.[215] Albeit in different contexts, what can be seen as the common feature in these cases is the fact that parental rights or wishes may be appropriately interfered with in the name of the best interest or welfare of the child. In other words, the Court has

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[211] Ibid, 757.

[212] Ibid, 759.

[213] David Ziebart, 'Jehovah's Witnesses – Medical Care, Minors and the Religious Rights' (2007) 19 Denning Law Journal 219, 239.

[214] *Re H (a child) (parental responsibility: vaccination)* [2021] 2 All ER 288.

[215] Ibid, 314.

authority to interfere with parental decisions wherever the Court regards the decision not in the best interests of the child.[216]

Whilst there is no doubt that the welfare principle as the paramount consideration (which considers the best interests of the child)[217] is the key test applied in the UK courts in cases regarding parental disputes or objections over some matters related to their children, some commentators have pointed out that in practice, when the best interests of the child are considered, it is likely that 'harm is very much at issue'.[218] As Diekema argues, only *harm to others* (not just merely being contrary to the child's best interest) justifies limiting a liberty right and this must be an effective last alternative.[219] He continues that consistent failure to satisfy a child's basic needs constitutes a harm, and only when this threshold is passed is curtailment of parental rights justified.[220] In line with this reasoning, Auckland and Goold also argue that it is right to let parents have the final say, 'respecting their unique responsibility for the child and their deep personal interest in his or her wellbeing' given that the choice that the parents made falls on weighing and balancing of multiple factors 'without exposing the child to significant harm'.[221] I argue that such arguments well apply in the context of reproduction where parents are exercising their reproductive rights. Although the concept of harm faces robust philosophical critique in the reproductive setting as I discuss below, what is the highlight here is that reproductive freedom should only be intervened by the courts or the state with higher level of threshold for intervention. Hence, no doubt that reproductive freedom should not be limited on trivial grounds (e.g. Robertson argues that those claims arising for 'yuck factor' in contending that the use of assisted reproductive technology is

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[216] Cressida Auckland and Imogen Goold, 'Parental Rights, Best Interests and Significant Harms: Who Should Have the Final Say Over A Child's Medical Care?' (2019) 78 Cambridge Law Journal 287, 292.

[217] As noted in Chapter 1, the terms of best interests and welfare are sometimes used interchangeably. For a brief revision on this, see section 1.3.3. of Chapter 1.

[218] Supra note 216, Auckland and Goold (2019) 323.

[219] Douglas S Diekema, 'Parental Refusals of Medical Treatment: The Harm Principle as Threshold for State Intervention' (2004) 25 Theoretical Medicine 243, 250-251.

[220] Ibid.

[221] Supra note 216, Auckland and Goold (2019) 312.

unnatural cannot be established to justifiably curtail reproductive freedom)[222] and that interfering with reproductive freedom is justifiable only for significant reasons, such as the prevention of significant harm to others.[223]

2.1.3 Parental rights in reproductive setting: Some further issues

- The philosophical complexity of "harm" of future children

It is still open to debate whether the use of technology (say, HGE) to bring about a particular type of child can in fact "harm" the child and as a result of this, limit the exercise of reproductive rights in such instance. Robertson points to several potential harms, including physical and psychological risks to the resulting children, that should be considered in the parental exercise of procreative liberty.[224] Yet, there remain some conceptual issues especially when the intended restrictions on parental rights are imposed based on the welfare of *future* children.[225] As Robertson acknowledges himself,[226] when the discussion involves future (unborn) children, it quickly invokes a philosophical paradox – that is the non-identity problem articulated by Derek Parfit where he highlights the difficulty explaining why certain decisions are morally wrong when the child owes his/her very existence to the decisions taken (see further Chapter 3).[227] It is sufficient to note now that if we accept the non-identity problem, then principally every use of reproductive technologies could fall within the sphere of parents' reproductive freedom because there cannot be a harm to bring a child to life if the only alternative for them is non-existence.[228] This observation appears to be a counter-intuitive one as may have indicated by Parfit himself when he argues for an alternative – a so-called 'Theory X' to be discovered

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[222] Supra note 172, Robertson (1994) 41.

[223] Supra note 181, Cavaliere and Palacios-Gonzalez (2018) 839.

[224] Supra note 191, Robertson (2004) 12.

[225] See for instance, supra note 147, Jackson (2002).

[226] Supra note 191, Robertson (2004) 13.

[227] Derek Parfit, *Reasons and Persons* (Clarendon Press 1984) 359.

[228] Supra note 165, Gavaghan (2007) Chapters 3 & 4.

to account for certain intuitively-felt wrongdoing generated from reproductive acts.[229]

Despite the controversy, it is suggested that it is coherent to consider a prospective parent having a strong concern for the well-being of future children if we endorse the protection of the 'future-oriented interests' – those in which a child may not exercise for the time being but can be satisfied later.[230] I stress that the right to use the technology within the protection of reproductive freedom should be a right to use it responsibly, considering the distinctive features of HGE. As highlighted in Chapter 1, one of the biggest concerns of the clinical use of HGE is that it is hard to predict accurately the possible side-effects (even if it passed the basic safety and effectiveness test for its use on animal models) until it is first used on actual human beings. Although this may be the case for any other clinical drugs or treatments, it is magnified in the case of HGE because any of these effects will be passed down to the next generations.[231] Where there is imminent harm that may be imposed (or no clear benefits to the children after the HGE procedure, as illustrated in scientist He's affair discussed in Chapter 1), then the exercise of reproductive freedom may be appropriately curtailed. The government should therefore intervene in this reproductive decision when the risks of significant harm clearly outweigh the benefits. This is in line with Green's view that parental autonomy should be exercised with the principle of beneficence[232] and non-maleficence to the future offspring.[233] The principle of beneficence and non-maleficence assumes, respectively, a moral obligation to do good and not to do harm to others.[234] Consequently, as the thesis suggests, interference in reproductive rights to use HGE may be legitimately inflicted

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[229] Supra note 227, Parfit (1984), 378.

[230] Joseph Stramondo, 'Disabled by Design: Justifying and Limiting Parental Authority to Choose Future children with Pre-Implantation Genetic Diagnosis' (2017) 27 Kennedy Institute of Ethics Journal 475, 479.

[231] Supra note 199, Ranisch (2019).

[232] It is not my intention to invoke the concept of procreative beneficence (the notion that parents have the moral obligation to select the "best" children as far as possible) in this instance. The idea of procreative beneficence is highly contentious that deserves lengthy discussion on its own. Julian Savulescu has famously written about procreative beneficence. See for instance, Julian Savulescu, 'Procreative Beneficence: Why We Should Select the Best Children' (2001) 15 Bioethics 413.

[233] Ronald Green, 'Parental Autonomy and the Obligation Not to Harm the Child Genetically' (1997) 25 Journal of Law, Medicine and Ethics 5.

[234] Tom Beauchamp and Jim Childress, *Principles of Biomedical Ethics* (5th edn, Oxford University Press 2001).

if the resulting child's life is expected to fall below a certain threshold which would tantamount to a form of harm (more on this in Chapter 3).

- Considerations for future children

Reproduction has broader effects other than just about the interests of procreator[235] in that it is about bring a new life into the world; in the case of HGE, it involves *deliberately creating* a certain kind of child to life who is going to live with any consequences of the technology. Thus, in this thesis, I maintain the position that considerations for future children may form a valid basis for the curtailment of parental reproductive freedom despite the philosophical paradox on "harming"[236] future children acknowledged by many commentators. As Gavaghan argues,

> 'we can meaningfully speak about harming people who do not presently exist, provided that we know or have strong reason to suspect that they will exist at some time in the future (…) the subjects of the harm in this case will develop interests, and it makes sense to consider whether our actions now will lead to those interests, in time, being thwarted or frustrated.'[237]

In practice, the regulations in the UK are, to some extent, already shaping reproductive decisions, especially in the context of assisted reproductive technologies.[238] As I mentioned in Chapter 1 (section 1.3.3), the concept of welfare – welfare of the potential child to be born – has been incorporated into the Human Fertilisation and Embryology Act 1990 (as amended in 2008) ("HFE Act") which

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[235] Supra note 176, Cavaliere (2020).

[236] I acknowledge that what is "harm" is debatable in the context of future children. See for instance, John Harris, *Wonderwoman and Superman* (Oxford University Press 1990) where Harris distinguishes 'harm' and 'wrong'; see also Anna Smajdor, 'How Useful is the Concept of the 'Harm Threshold' in Reproductive Ethics and Law?' (2014) 35 Theoretical Medicine Bioethics 321, Smajdor questions and discusses the implications of using harm threshold in regulating reproductive matter; see also James David Velleman, 'Persons in Prospect' (2008) 36 Philosophy & Public Affairs 221, 242 where Velleman argues against comparative harm, claiming that 'a harm should be something that makes sense for the person to regret, in proportion to the degree of harm'; see also Joel Feinberg, 'Wrongful Life and the Counterfactual Element in Harming' (1986) 4 Social Philosophy & Policy 143 where Feinberg claims that 'harm' can be interpreted as 'harmed condition' or 'harmful condition'.

[237] Supra note 165, Gavaghan (2007) 64.

[238] Ruth Deech, 'Reproductive Autonomy and Regulation – Coexistence in Action' (2017) 47 The Hastings Center Report S57.

regulates matters relating to assisted reproduction.[239] The welfare requirement restricts prospective parents' rights in the sense that the clinics are legally permitted to refuse treatment to those that they deem not suitable.[240] The exercise of reproductive freedom in having the kind of children they want via assisted reproductive services is clearly limited, for instance, in the case of PGD. Section 14(4) of the HFE Act 2008 prohibits the possibility for parents to choose to implant an embryo that carries a defective gene. Specifically, it provides that embryos that are known to have an abnormality 'must not be preferred to those that are not known to have such an abnormality'. In its explanatory notes, it is noted that, 'this would prevent assisted reproductive technology being used to select an embryo with a view to increasing the chance of giving birth to a child that had or would develop a serious medical condition'.[241] Taylor observes that the restriction on the use of PGD is likely if it was regarded to be 'detrimental to the welfare of the child'.[242] While there is an extensive and worth-noting debate on the normative position in preventing parental selection of certain type of embryos particularly from a disability studies point of view,[243] one can interpret the UK position as respecting individuals' choice to have a child (naturally) and raise him/her with the possibility to apply for public assistance if the child has a disability; but in the case of resorting to medical or technological resources to intentionally create a child with disability, it is viewed as not in the interests of the child.[244]

In sum, the UK strikes a good balance of promoting reproductive rights and considerations of future children in the field of assisted reproduction: research and

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[239] Kirsty Horsey, 'UK Government Proposes New Laws on Assisted Reproduction' (*BioNews*, 17 December 2006) <https://www.bionews.org.uk/page_90244> accessed 14 July 2021.

[240] Sally Sheldon, Ellie Lee and Jan Macvarish, ' 'Supportive Parenting,' Responsibility and Regulation: The Welfare Assessment under the Reformed Human Fertilisation and Embryology Act (1990)' (2015) 78 Modern Law Review 461.

[241] 'Explanatory notes on Section 14 of the Human Fertilisation and Embryology Act 2008' <https://www.legislation.gov.uk/ukpga/2008/22/notes/division/6/1/14> accessed 14 July 2021, para 114.

[242] Edward M Taylor, 'Procreative Liberty and Selecting for Disability: Section 14(4) Human Fertilisation and Embryology Act 2008' (2008) 2 King's Student Law Review 71, 74.

[243] See for instance, Gerard Porter and Malcolm K Smith, 'Preventing the Selection of "Deaf Embryos" Under the Human Fertilisation and Embryology Act 2008: Problematizing Disability?' (2013) 32 New Genetics and Society 171; Ailsa Stevens, 'Debating Deafness and Embryo Selection: Are We Undermining Reproductive Confidence in the Deaf Community?' (*BioNews*, 21 April 2008) <https://www.bionews.org.uk/page_91613> accessed 14 July 2021.

[244] Supra note 238, Deech (2017).

treatment are permitted as part of the exercise of reproductive freedom while it reserves the ability to apply limitations (via prohibitive legislation, or the rejection of a treatment or research license) if there is “harm” to others, including to the resulting children. It is clear that the philosophical paradox of “harming” future children has not stopped the legislators to regulate the technologies with future children being taken into consideration. In the context of HGE, similar approach will likely be (or, as this thesis advocates, should be) adopted. Notably, the probable disagreement is not on whether the welfare of future children will or ought to be a valid basis to limit reproductive freedom in using technology such as HGE, but rather on the question of what would constitute “harm” to future children to the extent that it is appropriate to justify limiting the exercise of reproductive freedom in the context of HGE.

While restrictions on reproductive technologies could also be applied for public good or social reasons,[245] this thesis concerns mainly on future children. In Chapters 3 and 4, I will further explore a so-called “well-being threshold” in light of HGE to understand the extent that this technology can and/or should be allowed in the clinical setting. Before moving on to the next chapter, there is another worrying issue commonly raised in the HGE debate that worth a brief discussion – that parents’ collective use of HGE would bring a new form of “eugenics”.

2.2 “Eugenics” in the Context of Heritable Genome Editing

The eugenic concern has been frequently raised in the ethical and legal debates on HGE. For instance, back in 1982, the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioural Research in its report on human genetic engineering notes that “altering the human gene pool by eliminating

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[245] For instance, Johnson and Petersen highlights the possibility to limit the genetic choices of the parents by regulating the assisted reproductive technologies on the ground of ‘public interest’. They identify the areas of public interest relevant to biotechnologies, such as health, financial and ethico-legal and socio-political concerns: see Martin Johnson and Kerry Petersen, ‘Public Interest or Public Meddling? Towards an Objective Framework for the Regulation of Assisted Reproduction Technologies’ (2008) 23 Human Reproduction 716, 719. Similarly, Buchanan and others argue that society has good reason to restrict individuals’ liberties if the exercise of those liberties would threaten a public good: supra note 180, Buchanan, Brock, Daniels and Wikler (2001) 183. Arguably, the public concern here relates to the concern on justice and equality. There is a particular concern about the negative impacts that might be imposed on people with disabilities if specific genes are deemed less favourable (see for instance, Tom Shakespeare, ‘Back to the Future? New Genetics and Disabled People’ (1995) 15 Critical Social Policy 22) and the concern if the use of HGE would increase the social inequality when only the rich can access the use of HGE (see for instance, Gregory Stock, *Redesigning Humans: Choosing Our Children’s Genes* (Profile Books 2002) 187).

"bad" traits is a form of eugenics, about which there is strong concern".[246] More recently, the UNESCO International Bioethics Committee in its 2015 report warns us against the eugenic dangers of genetic procedures which involve modifications for descendants. In particular, it implies that such a practice is contrary to human dignity.[247] However, there is an apparent lack of clarity on the term "eugenics". In its simplest form, "eugenics" can be understood as improving the human gene pool.[248] This loose definition is nonetheless not able to explain why there remains a strong unease with "eugenics". It is, therefore, worth looking at the eugenic issue before I make my claims in this thesis.

In this section, I first briefly outline the definition of "eugenics" and highlight how the fear of eugenics has arisen when contemplating the use of genetic technologies, including HGE, in reproductive settings. Next, I examine modern eugenics in which many proponents of such a notion dissociate it with the past eugenics (that is, during the Nazi era). It is worth clarifying here that in my thesis, I am not defending that children's welfare can (or should) be a valid ground to justify eugenic practice[249] (if we agree that HGE is a eugenic practice); instead in this thesis, I examine how a child-centred approach should be adopted in order to effectively safeguard children's interests in the context of HGE irrespective of whether HGE is indeed a eugenic practice or not. Prioritising children's interests in the context of HGE may in fact counter some of the eugenic concerns identified in this section. Since eugenic concerns have been commonly raised in the HGE debate, it is useful to first deal with this foundational controversy before exploring the research questions in this thesis.[250]

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[246] Supra note 1, President's Commission (1982) 47.

[247] International Bioethics Committee, *Report of the IBC on Updating its Reflection on the Human Genome and Human Rights* (United Nations Educational, Scientific and Cultural Organisation UNESCO 2015) <https://unesdoc.unesco.org/ark:/48223/pf0000233258_eng> accessed 29 December 2020, para 107.

[248] See for example, Ruth Chadwick, 'Genetics and Ethics' in Edward Craig (ed), *The Routledge Encyclopaedia of Philosophy* (London: Routledge 1998).

[249] See for instance William Dealey, 'The Eugenic-Euthenic Relation in Child Welfare' (1914) 19 American Journal of Sociology 835, 837 where Dealey explicitly argues that eugenics movement with the aim of producing 'genetically better children' can increase 'child welfare and happiness'.

[250] I do not examine the moral standing of "eugenics" and the plausibility of eugenic arguments made in the HGE debate in this thesis. For a thorough examination of eugenic arguments in HGE debate, see Robert Ranisch, ''Eugenics

2.2.1 "Eugenics": The notorious part of historical eugenics

It is hard to miss the name of Francis Galton in the literature related to "eugenics". Galton was the first to introduce the term in 1883.[251] In his later work, he defined eugenics as 'the science which deals with all influences that improve the inborn qualities of a race; also those that develop them to the utmost advantage'.[252] "Eugenics" can be understood as a science or a political and social initiative. When viewing "eugenics" as merely a study or science of improving inherited human traits,[253] it itself is supposed to be value neutral. It is when "eugenics" is seen as a deliberate, structured social movement or social policy[254] that things started to go astray (discussed more below). Eugenics is commonly divided into positive eugenics and negative eugenics. The former indicates improving or promoting some traits deemed desirable, while the latter indicates eliminating traits considered undesirable.[255]

If it is accepted that eugenics deals with the genetic improvement of the human population, then it is right that, as observed by Paul, 'virtually all medical genetics is eugenics'.[256] Just recently, Justice Clarence Thomas opined that abortion is an effective tool of 'eugenic manipulation' when refusing to review Indiana law on the ban of abortion on the basis of race, sex and disability.[257] Not only abortion, but Mahowald in her writing also acknowledges that negative eugenics has already taken

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is Back'? Historic References in Current Discussions of Germline Gene Editing' (2019) 13 Nanoethics 209, in which the author examines the types of eugenic arguments and questions the adequacy of comparing historical eugenics with HGE and the applicability of eugenic concern in the HGE debate.

[251] Francis Galton, *Inquires into Human Faculty and its Development* (Macmillan 1883) 17 where Galton first introduced the term "eugenics" to signify 'the science of improving stock'.

[252] Francis Galton, 'Eugenics: It's Definition, Scope and Aims' (1904) 10 The American Journal of Sociology 1, 1.

[253] Supra note 250, Ranisch (2019) 210, where the author acknowledges that Galton first understood "eugenics" as a science rather than a pernicious theory associated with certain social policies.

[254] As observed by Wilkinson, see Stephen Wilkinson, '"Eugenics Talk" and the Language of Bioethics' (2008) 34 Journal of Medical Ethics 467, 467.

[255] See for example, Mary Mahowald, 'Drawing Lines between Extremes: Medical Enhancement and Eugenics' (2006) 1 The Pluralist 19.

[256] Diane B Paul, 'Eugenic Anxieties, Social Realities, and Political Choices' (1992) 59 Social Research 663, 667.

[257] Melissa Quinn, 'Clarence Thomas: Abortion Has Potential to 'Become A Tool of Eugenic Manipulation'' (*Washington Examiner*, 28 May 2019) <https://www.washingtonexaminer.com/policy/courts/clarence-thomas-abortion-has-potential-to-become-a-tool-of-eugenic-manipulation> accessed 29 December 2020.

form in the modern technological world, such as in the prenatal testing and subsequent termination of pregnancy.[258] Following this, the use of HGE, even for the prevention of genetic diseases, can be properly labelled as "eugenics".

In the academic literature on HGE, the eugenic concern takes several forms. One type of argument debates whether HGE itself is a form of "eugenics" and whether it is morally justifiable.[259] The other kind of argument argues that the use of HGE for the prevention of genetic diseases may slide down to enhancement[260] and the latter gives rise to problematic eugenic concern.[261] It seems that "eugenics" bears the double-edged sword, for it is used by both advocates and opponents of genetic technologies to support their intended position. Advocates of the genetic technologies usually argue that the new eugenics (one which stresses an individual's liberty to exercise the choice to use the technology) is not like the old eugenics (often linked with the notorious Nazi regime); while the opponents of the genetic technologies usually claim that the new eugenics is just like the old eugenics.[262] Hence, "eugenics" is arguably a form of language used to manipulate the players in the field.[263] This leads some scholars such as Ranisch to conclude that it is the best if we leave "eugenics" out of the HGE debate as the existing arguments on eugenic concerns are 'ambiguous, partly contradictory, selective regarding history, and have a power of suggestion that must be deemed problematic in light of the ethical

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[258] Supra note 255, Mahowald (2006) 28.

[259] See for instance, Jurgen Habermas, *The Future of Human Nature* (Cambridge: Polity 2003), 21 in which Habermas differentiates the use of genetic technologies to prevent certain genetic conditions from eugenic purpose. This implies that the use of HGE for such purpose is not "eugenics". On the other hand, Resnik sees the use of genome editing for prevention of genetic diseases as a form of eugenics but one which is morally acceptable. See David Resnik, 'Debunking the Slippery Slope Argument Against Human Germ-Line Gene Therapy' (1994) 19 Journal of Medicine and Philosophy 23, 28. Also, see Nicholas Agar, 'Why We Should Defend Gene Editing as Eugenics' (2019) 28 Cambridge Quarterly of Healthcare Ethics 9 where Agar classifies human genome editing as "eugenics" but he argues that it is merely morally *questionable* instead of morally bad.

[260] As indicated in Chapter 1, the use of heritable genome editing for "enhancement" purpose in this thesis means the modification of genes related to non-medical traits like intelligence, height and eye colour and those related to transhumanism.

[261] See for instance, Theodore Friedmann, 'Genetic Therapies, Human Genetic Enhancement, and … Eugenics?' (2019) 26 Gene Therapy 351; Calum MacKellar, 'Gene Editing and the New Eugenics' (2018) 25 Dignitas 3. This form of argument is sometimes known as the slippery slope argument. See also, supra note 267, Resnik (1994).

[262] Giulia Cavaliere, 'Looking into the Shadow: The Eugenics Argument in Debates on Reproductive Technologies and Practices' (2018) 36 Monash Bioethics Review.

[263] Supra note 254, Wilkinson (2008); Lewis Petrinovich and Patricia O'Neill, 'Influence of Wording and Framing Effects on Moral Intuitions' (1996) 17 Ethology and Sociobiology 145.

requirement for transparency'.[264] Paul also shares this sentiment when she observes that "eugenics" connotes unsettled definitions[265] and it frequently 'reveals more about its user's attitudes than the policies, practices, intentions, or consequences labelled'.[266] In the genetics and reproduction debate (including HGE), the fear of eugenics is commonly identified with certain piece of the whole history, in particular, the past genocide in Nazi Germany.[267]

In the first half of the twentieth century, there were widespread eugenics programmes advanced by the state in which there was systematic abuse of reproductive rights and other human rights.[268] It is this history that has generated the current fear of "eugenics". One of the notorious historical events commonly associated with the name of "eugenics" is The Holocaust in Nazi Germany where it involved the mass killings of European Jews and other minority groups mainly driven by racial superiority and prejudice.[269] Other events which led to this extreme form of "eugenics" were those implemented in America which involved anti-miscegenation laws, immigration restriction, forced sterilisation intending to improve the population by getting rid of the less 'desirable' members of society (mostly criminals, poor, various ethnic groups and the disabled).[270] There were also considerable eugenics movement in Britain, including calling for bills that would legalise voluntary sterilisation of those 'undesirables'.[271] The historical eugenics in

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[264] Supra note 250, Ranisch (2019) 220. Others who have raised the confusion caused by the use of "eugenics" in the ethical debate on genetics technologies include Diane B Paul, 'What Was Wrong with Eugenics? Conflicting Narratives and Disputed Interpretations' (2014) 23 Science and Education 259; also, ibid, Wilkinson (2008).

[265] This may be partly due to a rich and complex history with "eugenics". See Maurizio Meloni, *Political Biology: Science and Social Values in Human Heredity from Eugenics to Epigenetics* (Palgrave Macmillan 2016) where Meloni highlights how eugenics practices have taken various forms throughout history and there is no uniform ideology. For a detailed account of eugenics history, see for instance, Alison Bashford and Phillipa Levine (eds), *The Oxford Handbook of the History of Eugenics* (Oxford University Press 2010).

[266] Supra note 256, Paul (1992) 665.

[267] Stephen Wilkinson and Eve Garrard, *Eugenics and the Ethics of Selective Reproduction* (Keele University 2013) 4.

[268] See for instance, Daniel Kevles, 'Eugenics and Human Rights' (1999) 319 British Medical Journal 435.

[269] Ibid.

[270] Ibid.

[271] For a detailed discussion on eugenics in Britain, see GR Searle, 'Eugenics and Politics in Britain in the 1930s' (2011) 36 Annals of Science 159; Victoria Brignell, 'The Eugenics Movement Britain Wants to Forget' (*New Statesman*, 9 December 2010) <https://www.newstatesman.com/society/2010/12/british-eugenics-disabled> accessed 26 January 2021.

this form is now widely criticised as an abuse of human rights with the presence of force. Such history explains why many view "eugenics" as hostile and morally objectionable.[272]

The attempts to oppose HGE by referring to the eugenic concerns based on this selective history invoke some doubts over the plausibility of such claims. For instance, Ranisch questions the adequacy of comparing historical eugenics to the practice of HGE, considering that there are different forms of eugenics theories apart from the 'racial hygiene' movement explained above.[273] Since the past eugenics[274] is usually deemed abhorrent, there are attempts to dissociate new genetics from the past eugenics.[275] There have been increasing views that new genetics, including the HGE technique, is 'new eugenics'.

2.2.2 Heritable genome editing as new eugenics?

> 'With the advent of a new way to modify humans – by transforming their genes, rather than through breeding and extermination – it's not overly alarmist to say eugenics, or whatever we call it this time, could come back, only in a new, private form shaped by the dynamics of democratic consumer culture'.[276]

This part considers the notion of modern eugenics by unpacking the above observation which highlights that human genome editing is a new form of eugenics. However, as noted earlier, due to various interpretations of "eugenics", it is yet to reach a complete consensus whether the development of science and genetics (including the technique of HGE) would precipitate a new form of eugenics.[277] If we

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[272] Supra note 267, Wilkinson and Garrard (2013) 4.

[273] Supra note 250, Ranisch (2019) 212.

[274] Although there is a rich history of "eugenics", when I refer to "past" or "historical" eugenics in the following writing, I mean those associated with the notorious events I briefly explained in this part.

[275] See for instance, Merryn Ekberg, 'The Old Eugenics and the New Genetics Compared' (2007) 20 Social History of Medicine 581.

[276] Daniel J Kevles, 'The History of Eugenics' (2016) 32 Issues in Science and Technology 45, 45. For a more comprehensive account on the relationship between advances in genetics and "eugenics", see Daniel J Kevles, *In the Name of Eugenics: Genetics and the Uses of Human Heredity* (5th edn, Harvard University Press 2004).

[277] See supra note 259 on the different interpretations on "eugenics" which lead to different conclusions on whether the employment of HGE is ethically acceptable or not.

agree to what is deemed the ‘heart’ of the concept of eugenics – attempts to improve the quality of the human gene pool[278] – then it is hard to deny the claim that HGE indeed is a form of eugenics in this sense.[279] The next question that should be asked is whether HGE is a form of new eugenics that can be morally defensible?[280] My proposition in this thesis is that the label of “eugenics” itself may not necessarily render the practice totally morally indefensible, although those practices with such a label do warrant our attention due to part of its notorious history. I stress that it is not the eugenics label that we should be cautious with, but the *potential abuses* associated with such a label. This understanding is important for my thesis because otherwise, the arguments made in subsequent chapters would be vulnerable to the criticism based on eugenics – either by claiming that HGE should be prohibited because it is eugenics or that it might lead to eugenic goals. In the following, I briefly explain a few of the features of new eugenics drawing from the observation by Kevles quoted above: that this form of new eugenics is private, democratic and market driven. Unpacking this is significant to better understand how HGE, even when seen as a form of new eugenics, can be distinguished from the past eugenics.[281]

There are two main differences between the historical eugenics and the new eugenics commonly observed in the literature. First of all, there has been notable progression of genetic and genomic knowledge and expanding knowledge in the field of epigenetics.[282] The past eugenics has been criticised for having based on flawed science about the role of genetics in determining human hereditary traits and behaviours.[283] The advance in scientific development has dramatically improved our

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[278] Supra note 254, Wilkinson (2008) 467.

[279] Supra note 275, Ekberg (2007).

[280] For a discussion on this question, see for instance, supra note 259, Agar (2019); Arthur L Caplan, Glenn McGee and David Magnus, ‘What is Immoral about Eugenics?’ (1999) 319 British Medical Journal 1.

[281] Such attempt is also seen in the 2015 report by the International Bioethics Committee where it is highlighted that the new eugenics should not be confused with the ‘barbarous projects of eugenics that planned the simple elimination of human beings considered as “imperfect” on an ideological basis’. See supra note 247, International Bioethics Committee (2015) para 111.

[282] Epigenetics is a study which focuses on the changes of organisms due to changes to gene expression inside the body caused by interaction of genes in the internal biological environment and the external social environment, see Danielle Simmons, ‘Epigenetic Influences and Disease’ (2008) 1 Nature Education <https://www.nature.com/scitable/topicpage/epigenetic-influences-and-disease-895/> accessed 06 August 2020. For a discussion on the relationship between eugenics and epigenetics, see supra note 265, Meloni (2016).

[283] Supra note 275, Ekberg (2007) 590.

understanding of genetics and genomics with higher accuracy than in the past decades.[284] Thus, the past accusation – that the eugenic movement is based on scientific errors – is less applicable in the modern era because the risk of false scientific view is significantly reduced (although the risk of abuse of scientific knowledge remains real).

Second, there is also a different socio-cultural, political and ethico-legal landscape in the modern era for how "eugenics" is practised.[285] Fox argues that the old eugenics is wrong not because it is coercive, collective or state ideology, but rather because there was an unjust infringement of 'individual autonomy, bodily integrity, and equality before the law'.[286] The liberal ethical values of respect for personal autonomy (including parental reproductive rights) and equality for all people are now widely recognised, at least, in the Western democratic countries. This new form of eugenics comes in the name of liberal eugenics, famously defended by Nicholas Agar.[287] The liberal eugenics is characterised as being voluntary, individualistic and state-neutral.[288] Fox observes that the ideal of liberal eugenics encourages 'a mildly perfectionist commitment to the value of autonomy' in which he sees autonomy as 'the capacity of the individual to make genuine choices among a meaningful range of life plans'.[289] The liberal eugenics thus assumes a more individualistic conception of autonomy in that it advocates that there should be extensive freedom (without direct force and state control) to use certain technologies including those that allow parents to choose the traits of their prospective children.[290] This fits Kevles' observation that the new eugenics takes place in a more private form with more democratic values.[291]

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[284] Ibid, 590-591.

[285] Julie M Aultman, 'Eugenomics: Eugenics and Ethics in the 21st Century' (2006) 2 Genomics, Society and Policy 28.

[286] Dov Fox, 'The Illiberality of Liberal Eugenics' (2007) 20 Ratio 1, 22.

[287] Nicholas Agar, 'Liberal Eugenics' (1998) 12 Public Affairs Quarterly 137, 137.

[288] Supra note 286, Fox (2007) 3.

[289] Ibid, 7.

[290] Supra note 287, Agar (1998) 137.

[291] Supra note 276, Kevles (2016) 45.

Nonetheless, if we consider a relational understanding of autonomy in which it takes into account internalised abuse and oppressive social surroundings which may diminish one's agency,[292] it is not that straightforward to determine whether a "eugenic" practice is coercive or not (or whether it is truly liberal or not) in reality. As Paul notes, there is a lack of agreement on what connotes "coercion" even though, in general, we can agree that coercion is objectionable.[293] This is partly because, also as Kevles observes, the new eugenics is now consumer or market driven. In such a setting, there are concerns if parents indeed are exercising real freedom (with no coercive element) in making their reproductive decisions. In the context involving assisted reproductive technologies, coercion may be related to how much autonomy can be practised in parents' reproductive choices.[294] From a relational perspective of autonomy, the voluntariness of parental choice can be questioned if, for instance, there are limited practical alternatives for prenatal screening or testing with abortion, or it may be the pressure from the cost-saving policies put in place by the private employers or insurance companies.[295] This concern can similarly arise when HGE becomes safe and effective for clinical use, where parents may be pressured to adopt the technique. The pressure comes not only from the private enterprise, but it may also come from societal and cultural attitudes. As Aultman points out, if there is a set of values and belief systems that seem to be widely applicable to all women in the community, women may feel pressured to conform to that standard (hence, not able to exercise reproductive freedom).[296] Also, if there is a social norm of "health", "attractiveness" or other traits, prospective parents may want to ensure the "desired" traits for their prospective children when the technology is feasible, and they may even 'demand the right to do so'.[297]

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[292] Natalie Stoljar, 'Feminist Perspectives on Autonomy' (2018) Stanford Encyclopaedia of Philosophy <https://plato.stanford.edu/entries/feminism-autonomy/#RelAut> accessed 29 December 2020.

[293] Supra note 256, Paul (1992) 670.

[294] Ibid.

[295] Ibid.

[296] Supra note 285, Aultman (2006) 40.

[297] Supra note 264, Paul (2014).

Following this, there is no doubt that some scholars would see the new eugenics as 'backdoor' eugenics in which it is viewed that eugenics can unfold itself tacitly and 'without actual intentions of the involved actors'.[298] Duster explains that the new eugenics 'will come by the back door of screens, treatments and therapies' and it will surface from individual choices or demands rather than direct social policy.[299] It must be noted that those decisions made in private may have wider population consequences if taken collectively.[300] This kind of eugenic effect though not unique to only HGE but also to other types of reproductive technologies, has magnified in the case of HGE, considering that HGE involves direct control of genes and it brings heritable effects.[301] Paul warns that this form of eugenics is more problematic as it is hard to effectively resist than is eugenics that comes with state enforcement.[302] Similarly, Wright also warns of the dangers from our expanded capacity for privatised eugenics in which parents are left with much freedom to choose the kind of children they desire.[303] Thus, the potential consequences with such increased capacity of parents with the advance of biotechnology must be carefully assessed. In particular, the possible abuse of eugenic practices, for instance, social and economic injustice[304] and promoting (perhaps implicitly) of discriminatory behaviour,[305] must be recognised and tackled. One possible way (one which is more relevant to the present

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[298] Supra note 250, Ranisch (2019) 219.

[299] Troy Duster, *Backdoor to Eugenics* (New York: Routledge 1990) x.

[300] Supra note 256, Paul (1992) 666. One example of this may be the widespread use of prenatal genetic testing in Iceland for genetic diseases such as Down Syndrome followed by a termination of pregnancy. The effect of such practice is that Iceland is 'close to eradicating Down syndrome births' (Julian Quinones and Arijeta Lajka, '"What Kind of Society Do You Want to Live in?": Inside the Country where Down Syndrome is Disappearing' (*CBS News*, 14 August 2017) <https://www.cbsnews.com/news/down-syndrome-iceland/> accessed 26 January 2021). Some has described the systematic termination of babies with Down syndrome in Iceland as 'modern eugenics' and is 'disturbing' (Evan Wilt, 'Modern Eugenics: Down Syndrome 'Eradication' in Iceland' (*World*, 21 August 2017) <https://world.wng.org/content/modern_eugenics_down_syndrome_eradication_in_iceland> accessed 26 January 2021).

[301] Supra note 250, Ranisch (2019) 211.

[302] Supra note 264, Paul (2014) 266.

[303] Robert Wright, 'Achilles' Helix' (1990) 203 New Republic 21, 27. Wright worries that once the genetic knowledge advances from being able to discover not only pathologies but also on traits like intelligence, then we might be marching towards a caste system.

[304] Supra note 285, Aultman (2006). Aultman identifies several problems with the past eugenics but highlights that justice is the main problem with the past eugenic practices and even the modern use of genetic knowledge and technologies.

[305] Andrea Lavazza, 'Parental Selective Reproduction: Genome-Editing and Maternal Behavior as a Potential Concern' (2019) 10 Frontiers in Genetics 1, 4.

thesis) to avoid potential abuses of the eugenic label imposed by the use of HGE is through a child-centred framework that could impose strict and justifiable limits to the employment of HGE as part of parental reproductive choices. For instance, as this thesis argues later, a health-based capability approach (see Chapter 4) can inform the policymakers in this respect by setting the boundaries for the future deployment of HGE.

2.3 Conclusion: Summary

The application of genetic technologies in human reproduction inevitably generates heated debates. Such debates require our attention especially as there has been significant scientific advancement with improved technological capacity in the field of genome editing. Not all these debates can be addressed in this thesis. For this reason, in this chapter, I set out my positionings on two foundational issues: the parental exercise of reproductive freedom in the context of HGE and the eugenic concerns in such a setting.

This chapter briefly discussed both issues and highlighted two main assumptions for this thesis. First, this thesis presumes that parents' rights to resort to HGE should prima facie fall within the protection of reproductive freedom and that it should only be intervened when there is significant harm, or a risk of significant harm to the resulting children. While I will further explore in later chapters what this "harm" could be in the context of HGE, the point I wish to have made in this chapter is that no doubt parental rights can be justifiably intervened on the ground of protecting children's interests and this includes future children's interests; considerations for future children's interests are likely to shape or influence the extent of parental exercise of rights in the use of HGE in the future, as can be seen in the existing regulations of assisted technologies in the UK. Next, it is warned that the extensive use of genetic technologies including HGE even in the private form as within the family might have wider population effects with eugenic concerns. As I highlighted, the proposed reproductive use of HGE even for the prevention of genetic diseases is hard to escape the label of "eugenics" if we agree to the core of eugenics which is the improvement of the human gene pool. Nonetheless, this thesis also presumes that having such a label itself does not necessarily lead to the conclusion that the procedure is morally unjustifiable, though close attention must be paid to the potential abuses that may arise from (modern) eugenic practice. Whilst these issues are pertinent to the overall HGE debate, I examine the ethico-legal issues in HGE via a child-centred approach where the discussion focuses on "children" instead of a parent-centred approach that focuses on parents' rights and a society-centred approach that focuses on social implications from new eugenics. Thus, in the next chapter (Chapter 3), I shift focus to several child-centric arguments in order to examine how "children" are positioned within the current HGE debate.

Chapter 3 – Heritable Genome Editing and Children: Existing Ethico-Legal Debate

In Chapter 1, I demonstrated that the science surrounding human heritable genome editing ("HGE") is advancing at a fast pace; hence the possible clinical use of this technique is becoming more imminent than ever. Accordingly, the ethico-legal debate on reproductive use of HGE has also become more urgent and imperative than before. In Chapter 2, I discussed the concept of reproductive freedom and highlighted that such a concept could be expanded to include the use of this technology. In other words, the reproductive use of HGE may fall within the protection of reproductive freedom. Nonetheless, I also noted that this freedom is not absolute in the sense that it should only be exercised if the decision to use such technology does not bring significant "harm" to the resulting children. As well as the concept of reproductive freedom, I also explored the concept of "eugenics" which, in its simplest form, connotes the effort of improving the human population. Many modern reproductive methods, including the possible clinical use of HGE, are seen as having eugenic implications. However, as argued in Chapter 2, being classified as "eugenics" itself does not necessarily suggest that the technique should be ethically unjustifiable. If we agree that "eugenics" is something to be cautious about, then there should be more explicit regulations in place to determine what can and cannot be done with the human genomes. What can be observed from the concept of reproductive freedom and the concept of "eugenics" is that both speak from the perspectives of parents and society (or state). Undeniably, these are important perspectives to the ethico-legal debate on the reproductive use of HGE. Nevertheless, "children" who are the actual subjects of this technology have not been given enough attention. In this chapter (and in fact, this thesis), I go beyond reproductive autonomy and eugenics and consider another approach in the HGE debate; that is a child-centred approach.

This chapter first explores how children are positioned in the existing debate on HGE in order to understand how children's interests have been considered to date. This issue can be mapped into two central questions in the general debate on HGE: first, whether the act of HGE is ethically acceptable at all; and second, how should we proceed with acceptable clinical use of HGE if the act of genome editing is deemed ethically justifiable? It is essential not to conflate these two questions in the ethical and regulatory discussion of HGE because each question raises different concerns; and most importantly, as Baylis highlights, the second question is more applicable if, or when, we, as a society, decide affirmatively that HGE is ethically appropriate.[306] In answering the first question from a child's perspective, there are three primary ethical arguments offered in which "children" are the focus: (1) the non-identity problem; (2) a so-called 'right-in-trust' for children in the form of open future principle; and (3) a purported right for an untampered genome. If we agree that HGE is ethically acceptable, then we can proceed to the second question regarding how a responsible clinical use of HGE should look when HGE is deemed safe and effective. One of the more common proposals suggested by many existing reports is (4) the need to have a long-term monitoring mechanism in place to safeguard the resulting children's interests. As I demonstrate, all of these approaches, albeit putting children as the focus, fail to appropriately safeguard children's interests. There are many questions left unanswered based on the current arguments, including what the appropriate limits are for using HGE: the non-identity problem seems to counter-intuitively suggest that there should be no limit on HGE as long as its use will cause the existence of the child (save for extremely rare cases where life is not worth living); the concept of "open future" leaves *too* much open for interpretations; the right to an untampered genome will, in theory, ban any applications of the HGE. Additionally, the long-term monitoring proposal is also dependent on children's knowledge of being born genetically modified to be effectively implemented. The latter is currently largely ignored in the debate and thus needs further exploration. This chapter addresses each of these in full and concludes with a summary of problems and gaps observed from the current arguments. Whilst all of these approaches are, on their own, inadequate as a child-focused means of regulating or guiding the use of HGE, they each have a kernel of utility in paving the way for the theoretical and normative discussions in my next few chapters concerning the capability approach (Chapter 4) and the concepts of "identity" (Chapters 5 and 6).

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[306] Francoise Baylis, 'Questioning the Proposed Translational Pathway for Germline Genome Editing' (2019) 3 Nature Human Behaviour 200.

3.1. How Children are Positioned in Current Heritable Genome Editing Debate?

In this section, I discuss four concerns which are the most relevant to children. In particular, I examine how children's interests are addressed in each of these arguments and whether their interests are appropriately safeguarded. I first examine one of the common arguments raised as an attempt to answer the question of whether the act of HGE itself (and/or a certain use of HGE) is ethically justifiable, that is the non-identity problem.

3.1.1 Can we ever "harm" future people by modifying their genes before birth? The non-identity problem

The use of technology in reproduction affects not only the conditions of the prospective children (e.g. whether they will be born with or without certain genetic diseases) but also their very "identity".[307] This indicates that the decision *not* to use the technology will lead to the birth of a different child with a different identity.[308] Following this, we may face difficulty in justifying why we opt for or against the use of certain technology for human reproduction because, in either choice, it is unlikely that we cause any "harm" to the resulting child because the child would not have been born at all without that technology. The dilemma in giving a justification for our decision in this kind of scenario is known as the "non-identity problem".

The non-identity problem is commonly considered when our ethical decision making relates to future people. One example, as already indicated above, in which our decisions (be it a decision from the prospective parents or government policy) affect the future individuals is the decisions relating to reproduction. Famously coined by Derek Parfit, the non-identity problem arises when our decisions influence the eventual individual who would come into existence.[309] It is a 'problem' because, as Parfit claims, there is difficulty in explaining why a decision is morally wrong when

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[307] See for instance, Matthew Liao, 'Do Mitochondrial Replacement Techniques Affect Qualitative or Numerical Identity?' (2017) 31 Bioethics 20.

[308] This claim, however, is not in consensus. It may be challenged in the case of HGE, depending on how we view "numerical identity". This issue will be further elaborated in Chapter 5.

[309] Supra note 227, Parfit (1984) 359.

that particular individual, albeit in a 'harmed' condition,[310] would not otherwise have existed but for such decision (discussed in more detail later).[311]

In this section, before I continue to outline an overview of Parfit's non-identity problem, I first identify a few preconditions which give rise to the non-identity problem in the first place. It must be stressed that the non-identity problem will only stand if we accept these preconditions. Subsequently, I examine the application (and possible implications) of the non-identity problem in the context of HGE, assuming that the preconditions for the problem are acceptable. My task here is to explore how this "problem" has come to dominate the reproduction-related debate and in particular, the HGE debate[312] and to suggest how we can go around the non-identity problem in the debate so as to satisfactorily consider the actual life that will be lived by the resulting children.

- Preconditions for Non-Identity Problem

The non-identity problem is premised on several conditions. I identify, from Parfit's discussion, that non-identity problem arises only when (1) we accept the time-dependence claim; (2) we rely on the person-affecting principle as a moral principle explaining harm and wrong; and (3) a so-called "numerical" identity is at stake. I elaborate each of these as follows. Once these preconditions are met, the non-

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[310] A "harmed" condition may be seen as a "flawed" existence which in Parfit's text refers to, for instance, a child born with disabling condition [see supra note 227, Parfit (1984) 358]; or individuals born in a subpar environment, say an environment where resources are depleted [Parfit (1984) 362-363].

[311] Ibid, 361-364; see also, Derek Parfit, 'Future Generations: Further Problems' (1982) 11 Philosophy & Public Affairs 113, 122.

[312] For suggestions on how to solve the non-identity problem, see for instance, David Boonin, 'How to Solve the Non-Identity Problem' (2008) 22 Public Affairs Quarterly 129; Eduardo Rivera-Lopez, 'Individual Procreative Responsibility and The Non-Identity Problem' (2009) 90 Pacific Philosophical Quarterly 336; Molly Gardner, 'A Harm-Based Solution to the Non-Identity Problem' (2015) 2 Journal of Philosophy 427; Melinda Roberts, 'The Nonidentity Problem' (Stanford Encyclopaedia of Philosophy 2019) <https://plato.stanford.edu/entries/nonidentity-problem/> accessed 27 December 2020). Solving the non-identity problem remains an issue that is far from consensus, see R Lawlor, 'Questioning the Significance of the Non-Identity Problem in Applied Ethics' (2015) 41 Journal of Medical Ethics 893. This is partly due to a complex philosophical account of "harm" and "wrong" which underlies the non-identity problem and the solutions to the problem (see again supra note 236 for a brief explanation).

identity problem assumes that existence is always good – a notion also subject to debate.[313]

a. The time-dependence claim

The non-identity problem only occurs if we accept the idea (so-called the "time-dependence claim" by Parfit) that if one had not been conceived at the particular time he/she was in fact conceived, then he/she would not have existed.[314] This suggests that if our parents had not met each other; or they had met and had sexual intercourse at a different time, it is likely that a different sperm would have fused with the ovum resulting in a different individual instead of ourselves.[315] Parfit claims that this idea is hard to argue against, at least intuitively.

b. The person-affecting principle of harm

Besides the time-dependence claim, the non-identity problem sustains only if we rely on and accept a person-affecting principle of harm. A person-affecting principle of harm can be articulated in terms of comparative harm. The idea is that there should be comparable states within which one can be compared in judging whether he/she has been harmed – someone is harmed when he/she is worse off than he/she would have been.[316]

In the non-identity cases, it is presumed that no one has been harmed – that particular child though born in an undesirable state (e.g. having a degenerative condition) is not harmed because had he/she not been born following that particular

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[313] See for instance, Nils Holtug and Peter Sandoe, 'Who Benefits? Why Personal Identity Does Not Matter in a Moral Evaluation of Germ-Line Gene Therapy' (1996) 13 Journal of Applied Philosophy 157; David Benatar, *Better Never to Have Been: The Harm of Coming into Existence* (Oxford Scholarship 2006). Benatar argues that it is possible to be harmed by being brought into existence. See also ibid, Feinberg (1986) 162-166. Feinberg raises doubt whether non-existence is indeed rationally preferable even in severely handicapped case. Also, see supra note 165, Gavaghan (2007) 93, where Gavaghan points to the case of life-prolonging treatment for children, in which the Court decided that 'life can be a burden rather than a benefit', citing the case of *Re J (A Minor)(Wardship: Medical Treatment)* [1991] Fam 33, 46.

[314] Supra note 227, Parfit (1984) 351.

[315] Ibid, 352. This also connotes the so-called, "Origin View" which states that "each person has this distinctive necessary property: that of having grown from the particular pair of cells from which this person in fact grew".

[316] See for instance, Justin Klocksiem, 'A Defense of the Counterfactual Comparative Account of Harm' (2012) 49 American Philosophical Quarterly 285.

choice, the alternative is not having been born at all. Following from this, existence is then, presumably, better than non-existence.[317] The non-identity effect then becomes a problem when we face difficulty explaining the intuitively felt wrong in certain choices leading to the birth of a particular person in a particular (often undesired) condition. The person-affecting principle of harm seems not able to provide a moral theory accountable for making the choice morally wrong despite the intuition that that particular individual has been "harmed" or "wronged" in some sense.[318]

c. "Numerical" identity is at stake

The third precondition for the non-identity problem deals with a particular conception of "identity" – numerical identity.[319] I shall further detail this concept of identity later in Chapter 5. Hence, for now, I only explain this concept in brief. In its simplest form, numerical identity can be understood by saying that an individual has the same numerical identity if he/she continues to exist despite change.[320] For instance, A who undergoes a kidney transplant is still A after the surgery. In other words, A is numerically the same even after getting a new kidney. Numerical identity is at stake in light of the non-identity problem because one of the reasons leading to this problem is based on the claim that different individual (individual with different numerical identity) would come into existence, depending on the decisions we make.

Assuming that the preconditions for the non-identity problem are accepted, I now continue with further elaboration on the problem itself.

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[317] As indicated earlier, this presumption is controversial (see supra note 313). This view is particularly against the anti-natalism philosophy, which claims that it is morally bad to reproduce because life brings suffering. For a brief understanding of this notion, see Elizabeth Brake and Joseph Millum, 'Parenthood and Procreation' (Stanford Encyclopaedia of Philosophy 2016) <https://plato.stanford.edu/entries/parenthood/> accessed 26 December 2020, para 2.1.

[318] Parfit himself notes that the moral principle (where he called it 'Theory X') that should explain the intuitively wrongful action or omission will not be in a person-affecting form. See supra note 227, Parfit (1984) 361.

[319] Tony Hope and John McMillan, 'Physicians' Duties and the Non-Identity Problem' (2012) 12 The American Journal of Bioethics 21, 22.

[320] See for example, David DeGrazia, 'Enhancement Technologies and Human Identity' (2005) 30 Journal of Medicine and Philosophy 261, 264.

- An Overview of the Non-Identity Problem

Before exploring how the non-identity problem is applicable to the HGE debate, it is essential to first understand what exactly this problem is. As indicated, if we accept the preconditions outlined above, the non-identity problem arises as we face the problem of justifying why certain actions or omissions are wrong to future people when their existence depends on that particular decision. The non-identity problem has important implications to the ethical discourse involving future individuals for as Wrigley explains, due to this non-identity problem, it is 'virtually impossible' to harm a future individual by any decision made before his/her conception even if that decision will lead to a (worth living) life with harmed condition.[321] In principle, this problem is applicable to both immediate and distant future generations, as long as the decisions would affect the (numerical) identity of those who come into existence.

Parfit explicitly applies this problem to the case of reproduction. He considers the decision of a woman to conceive a child (Child A) at a particular time knowing that such a decision will result in that child having a disabling condition that could have been avoided if she decided to defer the conception.[322] Parfit opines that most of us would agree that the woman should wait; however, should she have waited, there would be a different child (Child B) brought into existence instead of Child A.[323] In such cases, according to Parfit, it is difficult to explain why the decision to proceed with conception resulting in Child A is morally wrong (assuming that Child A might have disabling conditions but an overall worthwhile life).[324] Nonetheless, it is arguably morally wrong in most people's intuition to choose not to delay the conception. The problem we are facing is lacking a moral ground to justify this intuition. Just as Roberts explains, 'it is unclear on what ground of morality would

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[321] Anthony Wrigley, 'Harm to Future Persons: Non-Identity Problem and Counterpart Solutions' (2012) 15 Ethical Theory and Moral Practice 175, 175.

[322] Supra note 227, Parfit (1984) 358.

[323] Ibid, 359.

[324] Ibid.

insist that the choice to bring the one person into flawed existence is morally wrong'.[325]

Parfit's notion of the non-identity problem has then been extended to the contemporary debate relating to assisted reproductive technologies, including genetic technologies. In particular, this concern has been frequently raised in the ethico-legal debate on the use of preimplantation genetic diagnosis (PGD) where parents are allowed to screen and *select* certain embryos for implantation and HGE where parents may be offered the choice to have their gametes or embryos genetically *modified* before birth (the latter is this thesis' focus).[326] In the case involving embryos selection, the line of reasoning based on the non-identity problem is that selecting one embryo, say embryo X over another embryo Y, cannot be said to have "harmed" X even if it has disabling traits because X will not have existed if Y were selected instead.[327] I will not revisit here the debate concerning the selection of embryos; rather in the following, I examine whether and how would the non-identity problem be applied to the context of HGE where *editing* of embryos is at stake.

- Relevance of the Non-Identity Problem to Human Heritable Genome Editing

Alonso and Savulescu observe that there is an overlooked aspect in the non-identity literature, that is the difficulty in establishing what initiates a non-identity problem in practice.[328] This complication is particularly visible in the case of HGE. In the first instance, the application of HGE for human reproduction is a non-identity case

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[325] Supra note 312, Roberts (2019).

[326] See for instance, Glenn Cohen, 'Intentional Diminishment, the Non-Identity Problem and Legal Liability' (2008) 60 Hastings Law Journal 347; Kirsten Rabe Smolensky, 'Creating Children with Disabilities: Parental Tort Liability for Preimplantation Genetic Interventions' (2008) 60 Hastings Law Journal 299.

[327] See for instance, Benjamin Meir Jacobs, 'Is There a Moral Obligation to Select Healthy Children?' (2015) 41 Journal of Medical Ethics 696.

[328] Marcos Alonso and Julian Savulescu, 'He Jiankui's Gene-Editing Experiment and the Non-Identity Problem' (2021) Bioethics 1, 10.

because the use or non-use of HGE would affect the existence of a particular individual.[329] However, as I show here, this is not at all a straightforward issue.

Omerbasic argues that whether the non-identity problem applies in the context of HGE requires two-tier analysis in which one focuses on editing the embryos and the other focuses on the descendants of the edited "embryos". She argues that in the former, there is no genuine non-identity case because the parental decision to edit the genes of the embryo constitutes harm to the *selected* embryo (hence, there is no different numerical identity here) if something goes wrong (e.g. unexpected off-target effects from HGE) whereas for the latter, there is a non-identity problem because the descendants of the modified individuals owe their existence to the technology.

Omerbasic's view that editing *embryos* may not constitute a non-identity problem seems to be in line with the position of Wrigley, Wilkinson and Appleby in the discussion of mitochondrial replacement technique (MRT) in which they distinguish between the techniques of maternal spindle transfer and pronuclear transfer.[330] They argue that the non-identity problem arises in the application of maternal spindle transfer because the procedure is carried out before fertilisation of the egg, thereby leading to a different sperm fertilising the egg than the one that would have been fertilised without the procedure.[331] In the case of pronuclear transfer however, the non-identity problem, as it is argued, does not arise because the procedure happens after fertilisation (that is on the *elected embryos*).[332] If this view is accepted, one may argue, as with Omerbasic, that editing the human gametes may then affect who will be created eventually given that if there is any difference in the timing or other factors (e.g. the delay of time due to genome editing procedure), there could be another sperm that eventually fertilised the egg and thus another

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[329] Tomasz Zuradzki, 'Genetic Engineering and The Non-Identity Problem' (2008) 16 Diametros 63.

[330] Anthony Wrigley, Stephen Wilkinson, and John Appleby, 'Mitochondrial Replacement: Ethics and Identity' (2015) 29 Bioethics 631.

[331] Ibid, 635.

[332] Ibid.

individual would have come into existence instead; but this is not the case if the genetic intervention is done on the embryos when the fertilisation is complete.

Nonetheless, the position that editing *embryos* may not constitute a non-identity problem can be challenged. Rulli disagrees that this is the case in reality considering that the child will exist only because pronuclear transfer – that is the procedure done on embryos (instead of the gametes) – is chosen in the first place. Hence, it is not that obvious that editing the *embryos* should or can be distinguished from editing the *gametes* when contemplating the relevance of the non-identity problem. Specifically, in the context of HGE, Holm explains,

> 'In a context where gene editing is available to them, prospective parents will, with their clinicians, plan the IVF + gene editing, and it is very unlikely that this will happen at exactly the same time and in exactly the same way as it would have happened if gene editing had not been available, i.e., it is highly unlikely that exactly the same ova will be retrieved and fertilized by exactly the same spermatozoon.'[333]

Alonso and Savulescu examine whether there is a non-identity case (and thus a non-identity problem) in scientist He Jiankui's affair. As stated in Chapter 1, scientist He has genetically edited and implanted two embryos, resulting in the twins, Lulu and Nana. Alonso and Savulescu, as Holm, also take into account the process of IVF and egg and sperm selection that are carried out for the purpose of HGE. Hence, they argue that,

> 'gene editing was a necessary condition of Lulu and Nana's existence, because if Jiankui was not going to perform the gene edit, he would not have carried out the IVF, and the specific embryos from which Lulu and Nana were created would not have existed (or the chances of them ever existing would have been vanishingly small).'[334]

Following Holm, Rulli, Alonso and Savulescu's reasoning, it could be argued that the non-identity problem is relevant in the case of HGE despite the procedure is done on

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[333] Soren Holm, 'Let Us Assume that Gene Editing is Safe – The Role of Safety Arguments in the Gene Editing Debate' (2019) 28 Cambridge Quarterly of Healthcare Ethics 100, 105.

[334] Supra note 328, Alonso and Savulescu (2021) 9.

human gametes or early embryos. The decision to use and the act of HGE is thus necessary for the existence of the eventual resulting individuals and their descendants.

There is an important implication if we accept the non-identity problem in the context of HGE. Following the problem, it is hard to argue for what would be “harm” or “unsafe” for future individuals because the use of HGE may be the only way they can come into existence. Holm explains that the non-identity problem would lead to the conclusion that almost no uses of genome modification in reproduction can be deemed unsafe unless the procedure is so harmful that it brings a life not worth living.[335] This thinking is in line with some scholars who have relied on the non-identity problem and argued that it is always in the child’s best interest to be born.[336] This indicates that there should be no regulations or restrictions on the reproductive matters because any intervention will lead to a different child being born. For instance, Cohen agrees that it is problematic to justify any state regulation concerning reproduction using the best interest or child welfare test due to the non-identity problem.[337] Parker and Harris also express a similar notion that being born alive is always in the best interest of the child; thus, the welfare of the child is not capable of grounding the decisions in choosing between different children.[338] Hence, if we accept this line of thinking, then theoretically, the use of HGE will possibly harm *no* children because the (same identical) children would not have been born at all without the technology.

Nevertheless, I argue that this position has little practical contribution to the ethical and regulatory debate on HGE as it leads to an undesirable outcome with “children” left in a vacuum. Ethically speaking, it is far from satisfactory because it leads to the counter-intuitive claim that HGE should be allowed in almost any circumstances from the child’s perspective. This claim is counter-intuitive based on the fact that

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[335] Supra note 333, Holm (2019) 106.

[336] As mentioned earlier, the idea that to be born alive is always good is not without any controversy. See supra note 313 & 317.

[337] Glenn Cohen, 'Regulating Reproduction: The Problem with Best Interests' (2011) 96 Minnesota Law Review 423.

[338] Michael Parker, ‘The Welfare of the Child’ (2005) 8 Human Fertility 13; John Harris, ‘The Welfare of the Child’ (2000) 8 Health Care Analysis 27.

there is currently a massive discussion across the globe on the ethical acceptability and future use of HGE, suggesting that there are certain applications of HGE that should be further considered especially when the potential effects are heritable to future generations. Furthermore, as discussed below, from a legal perspective, the non-identity case has been demonstrated in the real-life so-called “wrongful life” claim.[339] Although it is the court decision that no such claim should be allowed (at least in the UK), some scholars point to the reality (instead of the philosophical side of the problem) that the emergence of such claims reflects that there are real-life actual people who are suffering from certain decisions made by parents or states and whose needs are to be considered. In the discussion that follows, I show that the application of the non-identity problem in deciding on a wrongful life claim unhelpfully dismisses the need to consider the real interests of children born via certain procedure. Hence, the ethico-legal debate on HGE should not be over-attached to the non-identity problem. Instead, it is possible to redefine the concept of “harm” so as to give a plausible account of why it is wrong to bring a child into existence in certain circumstances.[340] In this thesis, I argue that such a retort to the non-identity problem can be done based on a “well-being threshold principle” (more on this in Chapter 4).

- Non-Identity Problem and Wrongful Life Case

Not only does the non-identity problem arise in the realm of moral philosophy,[341] but it also echoes in the UK judiciary where the courts have been faced with the issue of whether mere existence can be a category of injury recognisable under the law (for instance, tort law). The existential question is apparent in the wrongful life cases – that is, cases where the resultant individuals sue against the other (e.g. the physician) for negligently causing him/her to be born – which involve the issue of whether it is preferable not to have been born at all from the child’s perspective.[342]

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[339] Charles Foster, Tony Hope and John McMillan, ‘Submissions from Non-Existent Claimants: The Non-Identity Problem and The Law’ (2006) 25 Medicine and Law 159.

[340] Supra note 327, Jacobs (2015) 697.

[341] For instance, see supra note 236, Feinberg (1986) 158. Feinberg indirectly expresses the non-identity problem as ‘especially serious philosophical one’ as one of the misgivings over wrongful life suits.

[342] See for example, ibid, Feinberg (1986) 158; Note however, there are also differing views. See W Ryan Schuster, ‘Rights Gone Wrong: A Case Against Wrongful Life’ (2016) 57 William & Mary Law Review 2329; also, Aaron-Andrew P

In this part, I explore the relevance of the non-identity problem in the wrongful life case. I shall point out that the UK court has dismissed the wrongful life case partly due to the non-identity problem. While it is not the task of this thesis to assess the credibility of a wrongful life claim and whether such cases should be accepted in tort law,[343] the reason that I raise the wrongful life cases here is to highlight the fact that there are wrongful life claims upon the court clearly indicates the real possibility that someone in real life may feel injustice and thus seeking for some sort of compensation for being born in certain conditions. Over-reliance on the non-identity problem to dismiss such a claim undesirably sidesteps the interests of children in their actual life.

In a wrongful life case, the legal action is brought by or on behalf of a (usually disabled) child. The claim is that due to defendant's (usually health care providers)[344] negligence in informing the parents or diagnosing the risk of disability, the defendant has caused the child's to be born.[345] It is not a claim that the negligence caused the disability but that the negligence caused the birth. To better understand the wrongful life case, it may be helpful to distinguish it from wrongful birth and wrongful pregnancy/conception cases. Both wrongful birth and wrongful conception, though controversial,[346] are recognised by the UK courts and they are

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Bruhl, 'Justice Unconceived: How Posterity Has Rights' (2002) 14 Yale Journal of Law & the Humanities 393, 410-411. Bruhl argues that non-identity problem is not a problem in wrongful life cases. This is because in wrongful life case, there is already an existing conception (thus a determinate though not yet born child) while in non-identity problem cases, the child is both not determinate and not yet born.

[343] For a more detailed discussion for and against wrongful life claims, see for example Carel JJM Stolker, 'Wrongful Life: The Limits of Liability and Beyond' (1994) 43 The International and Comparative Law Quarterly 521; Nora K Bell and Barry M Loewer, 'What is Wrong with 'Wrongful Life' Cases?' (1985) 10 The Journal of Medicine and Philosophy 127; Michael B Laudor, 'In Defense of Wrongful Life: Bringing Political Theory to the Defense of a Tort' (1994) 62 Fordham Law Review 1675; Rosamund Scott, 'Reconsidering "Wrongful Life" In England After Thirty Years: Legislative Mistakes and Unjustifiable Anomalies' (2013) 72 The Cambridge Law Journal 115.

[344] Note, wrongful life proceedings could potentially be initiated by the child against his/her own parents. See for instance, supra note 236, Feinberg (1986).

[345] Athena N C Liu, 'Wrongful Life: Some of the Problems' (1987) 13 Journal of Medical Ethics 69.

[346] It is controversial because the central issue facing the courts concerns with the unplanned child which implicitly indicates an "unwanted child". Although damages were rewarded to the parents in terms of pain and suffering due to pregnancy and childbirth; extra costs to raise a disabled child; and loss of autonomy in family planning, the courts were reluctant to award the costs of rearing an unwanted child because this will be contradictory to public moral and the views that a child should always be a blessing (see for instance, *McFarlane v Tayside Health Board* [1999] UKHL 50 where Lord Millett relied on the view that a child is a blessing and ruled that such joy should outweigh the burden of upbringing a child).

usually initiated by the parents.[347] In a wrongful birth case, the claim is that the parents would have terminated the pregnancy had the defendant not been negligent in advising the risk of disability (for instance, a negligently performed pre-natal screening) and as a result, a disabled child is born. On the other hand, as suggested by the title itself, "wrongful pregnancy" or "wrongful conception" relates to an unwanted pregnancy. This is usually raised in a negligently given contraceptive advice or a failed sterilisation surgery and the resultant child, though unwanted, is healthy.[348] The non-identity problem is more relevant to wrongful life cases where the claim is brought by or on behalf of the children instead of parents. As indicated earlier, the claim by the (usually) disabled child in a wrongful life case is that he/she would not have been born at all if not the healthcare professionals acted negligently.[349]

The key case regarding wrongful life claim in the UK is the case of *McKay v Essex Area Health Authority*.[350] In this case, the first claimant who was born with disabilities due to rubella initiated the proceeding claiming that the defendant had failed to detect the mother's (second claimant) condition and thereby allowed the child to be born alive in a disabled state. The mother would have terminated the pregnancy should she know that her child was infected by rubella. It must be highlighted that the first claimant's claim was that she should not have been born at all (instead of claiming that she should not have been born with disabilities). The Court of Appeal acknowledged the claim as one for wrongful life and refused to recognise such a claim. The Court was reluctant to recognise this form of "injury" under tort law as the majority opined that, inter alia, it is against the principle of

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[347] The key cases on wrongful birth and wrongful pregnancy cases in the UK are *McFarlane v Tayside Health Board* [1999] UKHL 50; *Parkinson v St James and Seacroft University Hospital NHS Trust* [2001] EWCA Civ 530; and *Rees v Darlington Memorial Hospital NHS Trust* [2002] EWCA Civ 88.

[348] For a more detailed explanation on the relevant UK cases on wrongful birth and wrongful pregnancy, see Rebecca Greenstreet, *A Practical Guide to Wrongful Conception, Wrongful Birth and Wrongful Life Claims* (Law Brief Publishing, 2018).

[349] See for instance, Ivo Giesen, 'The Use and Influence of Comparative Law in 'Wrongful Life' Cases' (2012) 8 Utrecht Law Review 35, 37.

[350] *McKay v Essex Area Health Authority and Another* [1982] QB 1166.

sanctity of human life,[351] there was no damage suffered by the first claimant,[352] and it would be impossible for the Court to evaluate the value of non-existence with existence in a disabled state.[353] The Court felt that this issue involves deeply philosophical questions about the meaning of life and thus is beyond the judicial realm.[354] Although the phrase "non-identity problem" is not raised in the legal case, the indication that the comparison is not between healthy existence and existence in a disabled condition but that between non-existence and a disabled existence;[355] and the sentiment that 'if the defendants had not been careless, the child would not be suffering now because it would not be alive'[356] echo what has been the gist in the non-identity problem. This is as observed by Cohen in which he suggests that this problem has, in part, led to the rejection of the wrongful life claim because there seems to be no reasonable ground to claim that the child is "harmed" by coming into life when non-existence is his only alternative.[357]

Nonetheless, it must be stressed that the *occurrence* of wrongful life claims clearly demonstrates that the non-identity problem is not necessarily a philosophical issue left only in the hands of philosophers; it also reflects the real dilemma some people (like wrongful life plaintiffs) faced in real life. Liu observes this in which she claims that although the reluctance of the court to accept wrongful life claim is understandable, the existence of such a claim corresponds to the reality that there are children suffering from painful conditions and compensation is sought in order to

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[351] Ibid, 1180H, 1188C.

[352] Ibid, Stephenson LJ, 1181C where it is held 'the only way in which a child injured in the womb can be compensated in damages is by measuring what it has lost, which is the difference between the value of its life as a whole and healthy normal child and the value of its life as an injured child. *But to make those who have not injured the child pay for that difference is to treat them as if they have injured the child, when all they have done is not having taken steps to prevent its being born injured by another cause*'. (my emphasis); Ackner LJ, 1189D.

[353] Ibid, Stepheson LJ, 1181E; Ackner LJ, 1189D; Griffiths LJ, 1192G. There are also other factors that the court considered, for instance, there cannot be a duty owed to the child on part of the doctor to terminate a foetus' life, the possible ramification in discriminating against people living with disabilities should the claim succeed (see 1180G-1181A).

[354] Ibid, Griffiths LJ, 1193C.

[355] Note however, in Bonnie Steinbock, 'The Logical Case for "Wrongful Life"' (1986) 16 The Hastings Center Report 15. The author argues for another interpretation on the wrongful life claim in which it does not involve comparing existence with non-existence.

[356] Supra note 350, *McKay* (1982) Stephenson LJ, 1184G.

[357] See supra note 337, Cohen (2011) 443 & 517.

make their living conditions (or in other words, their existence) more comfortable and bearable.[358] This, I emphasise, should be taken into account in considering the use of HGE. Hence, even if we accept that the non-identity problem is applicable in the case of HGE, our focus on the evaluation of its ethical applicability should be on the practical life that the child will be born into. In other words, the focus of whether the use of HGE should be clinically allowed should not be based on existence or non-existence, but on the kind of life that will eventually be lived by the resulting children. This is in line with what is indicated earlier in section 13(5) of the Human Fertilisation and Embryology Act 1990 (as amended in 2008) where Parliament has imposed a duty on the fertility treatment clinics to consider the welfare of the future child before providing services to the couples. As Gavaghan puts it, ‘implicit in such a provision is the assumption that, in certain circumstances, it is foreseeably in the interests of a potential future child to be spared existence, or that the life of such a child, were it to be created, would contain such a balance of harms over benefits’.[359] Although HGE may not be offered as part of fertility treatment and may not fall under section 13(5), the current position in the law suggests that it is not a far-fetched idea to consider the future life that is going to be lived by the resultant children. In line with this thinking, Meyer argues that an action or omission can harm someone if the act or omission causes the person’s life to ‘fall below some specified threshold’.[360] This reflects Kavka’s notion of ‘restricted life’ in which he sees it as a life worth living but that is ‘significantly deficient in one or more of the major respects’.[361] In a similar vein, Steinbock also stresses the importance of the very ‘basic interests’ to be protected at birth in order for one to have a ‘minimally decent existence’.[362] (I shall further explore this line of thought in Chapter 4 using a capability approach). Although the exact “threshold” on what is best for the future

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[358] See supra note 345, Liu (1987) 72.

[359] Supra note 165, Gavaghan (2007) 97.

[360] Lukas H Meyer, ‘Historical Injustice and the Right of Return’ (2004) 5 Theoretical Inquiries in Law 305, 308. What is the threshold is less clear, he merely suggests a specified threshold of ‘well-being’; See also, Seana Valentine Shiffrin, ‘Wrongful Life, Procreative Responsibility, and the Significance of Harm’ (1999) 5 Legal Theory 117, 123-124; E Haavi Morreim, ‘The Concept of Harm Reconceived: A Different Look at Wrongful Life’ (1988) 7 Law & Philosophy 3, 23-24, where Morreim emphasises that ‘certain harms reside in a substandard of state of affairs itself, not deriving from how that state of affairs is evaluated in comparison with how things could have been’.

[361] Gregory S Kavka, ‘The Paradox of Future Individuals’ (1982) 11 Philosophy & Public Affairs 93, 105.

[362] Supra note 355, Steinbock (1986) 19.

persons is open to debate,[363] this at least shows that we can evaluate certain actions, even if the pre-conception events are identity-determinative (in the sense that the person would not have existed if the action or omission had not been carried out).

So far, my point has been that emphasis on the non-identity problem when considering the possible use of HGE for reproduction is inadequate from a child-centred perspective. The emergence of wrongful life claims clearly indicates that there are voices to be heard in reality. Hence, a retort to the non-identity problem is essential in the HGE debate to properly regard the interests of the prospective children who would actually live the consequence of any decision made in relation to such procedure. In Chapter 4, I discuss how we can consider the prospective life that the resulting children are going to have by taking a capability approach; and in Chapter 5, I further elaborate on the notion of "numerical identity" and argue that the fact that the non-identity problem is preconditioned upon numerical identity does not increase its credibility in the HGE debate.

Only when we acknowledge the problem of over-relying on the "non-identity problem" in considering the potential reproductive use of HGE, can we plausibly shift our attention to other kinds of argument, for instance, the open future argument and the alleged right to unaltered genetic makeup before birth (discussed below). Otherwise, these arguments may be easily dismissed in parallel with the non-identity problem by claiming that no one can be harmed (even with a "narrow" future or one with intentional genetic modification done before birth) because he/she would not have been born at all if not the choice made on HGE. I now examine the open future argument.

3.1.2 Protecting children's future: the open future argument

Since HGE has the potential to impact the lives of the resulting children, one of the arguments in considering the ethical acceptability of its clinical reproductive use is whether (and how) it would affect the future options available for children. This line of argument commonly relies on the notion of a right to an open future, first formulated by Joel Feinberg. The crux of such a notion is that the future choices of

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[363] See for instance, Ori J Herstein, The Identity and (Legal) Rights of Future Generations' (2009) 77 The George Washington Law Review 1173, 1208.

children should remain open. Accordingly, when considering whether the human reproductive technologies (including genetic technologies) should be employed for certain purposes, the open future argument is frequently raised to contemplate the ways in which (if any) the technologies would affect the future options for children and to what extent this should be allowed. It is therefore important to address how the open future argument has taken its place in the existing debate on HGE in light of children's interests.

In what follows, I first provide a general overview of the right to an open future. I then explore the applications of the open future argument in the debate on HGE. The question I ask is whether the notion of an open future constitutes a suitable ethical guiding tool in such a context. I argue that despite the reformulated version of the concept of the open future, this concept remains too ambiguous to guide the parents (any other third parties) in making decisions in relation to the ethical use of HGE, thus failing to adequately safeguard the children's interests. Nonetheless, as I highlight, the idea behind the open future concept – that is, to protect the future opportunities available to the children – is indeed useful in the context of HGE in safeguarding the resulting children's interests, although more refinement is needed in order to properly set boundaries for an ethical use of HGE (I shall discuss how a capability approach can capture the future opportunities to future children born as a result of HGE and at the same time provide limitations to its use in Chapter 4).

- *Feinberg's Child's Right to An Open Future: An Overview*

As indicated, Joel Feinberg was the first to formulate the notion of a child's right to an open future, in the form of a right-in-trust (right that one cannot exercise just yet but will be able to exercise it when he/she reaches the age of majority).[364] The rights-in-trust resemble the rights conferred on adults but are specifically for children.[365] According to Feinberg, the right-in-trust is susceptible to others' infringement before the child attains the necessary capacities (e.g. physical and mental capacities) to exercise the right. A right to select one's own spouse is one

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[364] Joel Feinberg, 'The Child's Right to An Open Future' in Aiken W and Lafollette H (eds), *Whose Child? Children's Rights, Parental Authority and State Power* (Rowman and Littlefield 1980) 125-126.

[365] Ibid.

example of a right-in-trust: children may lack the legal and social ground to claim such a right, although it is generally agreed that they should have that right once they reach adulthood with legal capacity. Thus, during childhood, children should have the right *not* to be betrothed to someone so that the possibilities for them to select their own spouse in the future are not hindered.[366] As Feinberg proposed, a group of rights-in-trust would then be 'the right to an open future'.[367]

Feinberg discusses the notion of a child's right to an open future in relation to a US Supreme Court case of *Wisconsin v Yoder*[368] which dealt with parental religious upbringing of Amish children. The Amish place emphasis on their own upbringing in the community with strong religious convictions following the Bible.[369] Following this, the Amish parents in the case were reluctant to comply with the State law which requires compulsory high school education for their children because they believed that higher education was not essential to live their traditional way of life, which focuses on manual work.[370] Feinberg criticises the Supreme Court's decision to uphold the Amish parents' right to keep their children from mandatory school attendance, which was mainly based on the parents' freedom to exercise their religion. He observes that 'an education that renders a child fit for only one way of life forecloses irrevocably his other options'.[371] Feinberg reasons that the decision should have been to let Amish children 'reach maturity with as many open options, opportunities, and advantages as possible'.[372] He later argues that education (by parents and the state) should equip children into the adult world 'with as many open opportunities as possible, thus maximising (the children's) chances for self-fulfilment'.[373] It is suggested that these expressions by Feinberg connote a *strong*

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[366] Dena Davis, 'The Child's Right to An Open Future: Yoder and Beyond' (1997) 25 Capital University Law Review 93, 94.

[367] Supra note 364, Feinberg (1980) 124.

[368] *Wisconsin v Yoder* (1972) 406 US 205.

[369] Supra note 364, Feinberg (1980) 130.

[370] See supra note 368, *Yoder* (1972).

[371] Supra note 364, Feinberg (1980) 132.

[372] Ibid, 130.

[373] Ibid, 134-135.

interpretation of the right to an open future whereby it would require maximising future options for the children and that almost all the choices that might be made by the autonomous adult that a child could become must be preserved.[374]

While Feinberg's discussion on the right to an open future was made in the context of obligations to children in terms of education and/or upbringing, Dena Davis applies this right to an open future to the reproductive technologies and in particular, to the genetics context (genetic selection and genetic counselling). Davis argues that there is a substantial violation of such a right when parental shaping 'takes the form of a radically narrow range of choices available to the child when she grows up'.[375] In the case of intentionally selecting for a deaf baby, she argues that even if deafness is seen as a cultural identity instead of a form of disability, the future is 'an exceedingly narrow one'.[376] This is wrong because, as she argues in line with Feinberg's thoughts on the Amish education system, the decision would constrain the child born to a narrow group of people with limited choices.[377] In particular, that decision has constrained the future options for the child to the world of deafness without considering the options the child may have outside the world of deafness.[378]

If rights are designed to protect certain interests, then the right to an open future is allegedly based on the interest of children 'being the author of their own lives and/or developing their potential'.[379] Schmidt suggests that it is in the best interests of children to be able to determine their own future and thus it is also in the best interests of children if parents do not act in a way that limits children's chances to develop different future options in life.[380] Although it remains unclear how "open"

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[374] Joseph Millum, 'The Foundation of the Child's Right to an Open Future' (2014) 45 Journal of Social Philosophy 522, 525-526.

[375] Dena Davis, 'Genetic Dilemmas and the Child's Right to an Open Future' (1997) 28 Rutgers Law Journal 549, 567.

[376] Ibid, 570 & 574.

[377] Ibid, 575.

[378] Ibid.

[379] Jason Chen, 'The Right to Self-Development: An Addition to the Child's Right to an Open Future' (2016) 47 Journal of Social Philosophy 439, 442.

[380] Eric B Schmidt, 'The Parental Obligation to Expand A Child's Range of Open Futures When Making Genetic Trait Selections for Their Child' (2007) 21 Bioethics 191, 197.

the opportunities should be (see below), the discussion so far indicates that the right to an open future can be seen as both a negative and positive claim. A negative right connotes that there should be no interference of the right by a third party[381] whilst a positive right connotes that the third party should take active actions so that such right can be exercised by the child.[382] A right to an open future, if taken in its negative form, would mean that there is an infringement of the right when a deliberate action or omission significantly narrows the range of options available to the resulting children,[383] so there would be an obligation not to act in such a way that curtails the future choices available to the children. If taken as a positive form, it would entail an obligation to act in such a way that promotes the future ability of the children so that they are able to exercise their rights to exercise choices.[384]

A right to an open future is closely related to children's (future) "autonomy".[385] According to Feinberg, 'personal autonomy' can loosely be defined as 'self-rule', 'self-determination', 'self-government' and 'independence'.[386] In addition to seeing autonomy as a capacity in itself, Feinberg also highlights the conditions to be autonomous, including a blend of self-possession, distinct self-identity, authenticity and self-creation (self-determination).[387] Despite the various concepts of autonomy, Chen argues, as indicated earlier, the child's right to an open future is justified by at least one interest that should be protected: that is the child's interest to be

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[381] See for instance, Joyce C Havstad, 'Human Reproductive Cloning: A Conflict of Liberties' (2008) 24 Bioethics 71, 73.

[382] See for instance, supra note 374, Millum (2014).

[383] See for instance, supra note 375, Davis (1997) 567.

[384] Note, it is debatable on whether and how the parents can fulfil such an obligation for a positive right of an open future. See for instance, Claudia Mills, 'The Child's Right to an Open Future?' (2003) 34 Journal of Social Philosophy 499.

[385] Note, however, it is possible to interpret the right to an open future based on the concept of authenticity instead of autonomy. See Scott Altman, 'Reinterpreting the Right to An Open Future: From Autonomy to Authenticity' (2018) 37 Law and Philosophy 415.

[386] Joel Feinberg, *The Moral Limits of the Criminal Law: Harm to Self* (Oxford Scholarship Online 2003). There is an extensive debate on the concept of autonomy, and it is beyond the scope of this thesis to comprehensively analyse this concept. For more details, see for instance, Gerald Dworkin, 'The Concept of Autonomy' (1981) 12 Grazer Philosophische Studien 203; Thomas May, 'The Concept of Autonomy' (1994) 31 American Philosophical Quarterly 133.

[387] Ibid, Feinberg (2003) 31-44.

his/her own author of life and/or develop his/her potential.[388] Following this, the notion of open future thus emphasises the importance of children *being able* to grow into autonomous adults and choose from a range of opportunities and life plans. It must be noted that children having a variety of choices or opportunities when becoming an adult is different from children having different developed capabilities that lead to a variety of options. The former sees children as becoming future adults while the latter focuses on children as present beings. It is doubtful if Feinberg did capture the latter in his work as it has been suggested that the right to an open future sees the children as future adults.[389] In line with this, Cowden observes that the interests of the present children seem to have been disregarded in Feinberg's construction of the right-in-trust (and thus including the right to an open future) since he focuses on the future rights of the adult-self.[390] Cowden argues that it is not the future interests that we are concerned with, but the child's present interests 'to develop capacities and competencies into the future'.[391] It is this experience of the child during childhood in leading to more developed capabilities that I would like to emphasise in my thesis (discussed further in Chapter 4). This is despite the fact that it is always the "future" interests that seem to be at stake in the case of HGE since it is the future children that we are contemplating. If we accept Cowden's view, then we may need to conceptualise "autonomy" in a way that can justify thinking about children with "autonomy". In this setting, a relational understanding of autonomy will be helpful. A relational conception of autonomy stresses that, as Mackenzie observes, promoting autonomy is not just about 'mere proliferation of choice' but with 'how opportunities are socially distributed and with whether people have an adequate range of genuine and significant options available to them'.[392] In this sense, autonomy is seen closely connected with the society in which it draws

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[388] Supra note 379, Chen (2016) 442.

[389] See for instance, Jeremy R Garrett and Others, 'Rethinking the "Open Future" Argument against Predictive Genetic Testing of Children' (2019) 21 Genetics in Medicine 2190, 2190.

[390] Mhairi Cowden, *Children's Rights: From Philosophy to Public Policy* (Palgrave Macmillan 2016) 73.

[391] Ibid.

[392] Catriona Mackenzie, 'The Importance of Relational Autonomy and Capabilities for an Ethics of Vulnerability' in Catriona Mackenzie, Wendy Rogers and Susan Dodds (eds), *Vulnerability: New Essays in Ethics and Feminist Philosophy* (Oxford University Press 2014) 44.

attention to the social conditions and support for the development of autonomy.[393] This thinking is in accordance with my later argument in this thesis, where I stress that it is the *capabilities to* autonomy (rather than just autonomy) that should be focused on in the discussion of HGE (see further Chapter 4).

Setting aside the construction of rights of the open future, the notion of "open future" creates further conceptual and practical ambiguities even if we accept the right as it is. The first ambiguity concerns the interpretation of an "open" future and a "closed" one. Mills argues that it is onerous to determine an "open" future with 'a variety of options' in any meaningful way because it is undeniably a matter of perspective on whether those options do ensure an "open" future.[394] It is, therefore, hard to draw a line in what is "open" or "closed" future. Determining that a person has a "closed" or limited future just because they have a genetic-related condition is thus arbitrary and it also risks being biased and discriminatory. There are real-life examples to demonstrate that it is reasonable to claim that individuals living with genetic conditions need not be living a closed future. For instance, Nick Vujicic an Australian man born with Tetra-Amelia Syndrome[395] (a rare genetic disorder with no arms and legs) is now a well-known motivational speaker and best-selling writer.[396] There is also evidence showing that people with Tetra-Amelia Syndrome can carry out tasks from routine (e.g. putting make up on, brushing teeth, making the bed) to non-routine like drawing.[397] Hence, people with a genetic disorder (even with a physical disability) do not necessarily live a closed future.[398]

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[393] Ibid, 41.

[394] Supra note 384, Mills (2003) 499 & 501.

[395] Genetics Home Reference, 'Tetra-Amelia Syndrome' (2019) <https://ghr.nlm.nih.gov/condition/tetra-amelia-syndrome> accessed 26 December 2020.

[396] Life without Limbs, 'Nick – Bio' (2019) <https://www.lifewithoutlimbs.org/about-nick/bio/> accessed 26 December 2020

[397] See for instance, Truly, 'Life without Limbs: Zuly Sanguino's Extraordinary Story' <https://www.youtube.com/watch?v=Y1ayNidg36s&ab_channel=truly> accessed 26 December 2020.

[398] Again, as first indicated in Chapter 1, the social model of disability suggests that the social context (for instance, the social and political structure) has a strong implication on how the people with genetic-related disorders live their life. Their life may be impacted because of the set-up of certain social setting and not because of the disorder itself. See supra note 92, Hughes and Paterson (2010).

The second ambiguity relates to the possible ramifications of the "open" future. Mills argues that such a notion is 'confused, impossible and often pernicious'[399] and it will be burdensome for the parents to keep all options open.[400] This criticism is based on a *strong* interpretation of Feinberg's open future where it indicates *maximising* the future options for the children. Mills claims that it is the variety of choices that should matter, rather than the number of choices.[401] This leads to a more welcoming interpretation of Feinberg's open future which takes a *moderate* view. On this moderate interpretation, the focus is on the reasonable range of future instead of the maximum number of options. For instance, Millum argues that the right to an open future plausibly requires 'the provision of some reasonable range of options, not the largest possible range'.[402] Similarly, Lotz argues that parents should only 'seek, within their capacity, to provide adequate conditions for a child's emerging autonomy', implying that parents are not expected to provide a maximum number of life options for their children.[403] It is, however, still subjective and not determinative as to what should fall within the 'reasonable range'. But this understanding may at least address Mills' concerns, for it lightens the burden of parents in supplying the greatest amount of life choices for their children.

The third ambiguity (and related to the previous points) is a lack of methodology given by Feinberg in determining the "open" future.[404] Hence, we are left not knowing the open future, be it quantitatively or qualitatively. As indicated, despite the criticisms on "open" future and with the subsequent suggestions of "reasonable" or "meaningful" future, there is still a lack of proper parameters for how to determine "open" or "reasonable" future. Even when there is a shift from

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[399] Supra note 384, Mills (2003) 508.

[400] Ibid, 499-500. Note that a right to an open future here is argued in the context of *existing* children.

[401] Ibid, 500-501; Mianna Lotz, 'Feinberg, Mills, and the Child's Right to an Open Future' (2006) 37 Journal of Social Philosophy 537, 546; supra note 200, Sparrow (2012) 365. Sparrow argues that it is the 'worth' of the options that matters when it comes to evaluating the value of different options sets.

[402] Supra note 374, Millum (2014) 534. See also, supra note 200, Sparrow (2012) where Sparrow, instead of 'open future', argues for a right to a 'decent future' in which parents should be concerned with a reasonable selection of 'valuable life options' for the children.

[403] Supra note 401, Lotz (2006) 546.

[404] Supra note 374, Millum (2014) 523.

quantifying the choices to its quality aspects,[405] there is still a lack of guidance on *which* kinds of life options deserve (ethical and/or legal) attention. Affdal and Ravitsky suggest that the best interest standard is suitable for decisions affecting the child's open future. This is because the best interest test considers children's welfare that goes beyond the medical interests (it can cover, to cite only a few, psychosocial, cultural, relational-related interests), thus allowing a thorough analysis of the implications of a decision for 'the future ability of the child to access the fullest range of life experiences'.[406] The best interests test methodology seems appealing at first. But since it can cover factors beyond medical interests to psychological, social and many other interests, it is then arguable that the open future language is redundant here because the best interest language itself may be sufficient to be the determining standard in judging whether parents and/or any other third parties have made ethical (or unethical) decisions affecting children. Furthermore, the existing provisions under the United Nations Convention on the Rights of the Child which protects the substantive rights may help clarify what amounts to the "best interests" of children, hence the concept of best interest in this sense is arguably less vague than the concept of open future. That being said, this thesis does not argue that the best interests of children should be the *ultimate* determining standard in considering the possible ethical applications of HGE since the practicality of the best interest concept itself is subject to wide debate.[407] Rather, as suggested earlier, this thesis highlights the future abilities given by the opportunities available to the children. Thus, I explore the "capability approach" in Chapter 4 and demonstrate how it may be a better approach for considering the children's interests in the context of HGE.

For these reasons, I further argue below that it is not entirely clear how the act of HGE (be it for the use of disease or non-disease traits) can adversely affect the "open future" of the resulting children rendering them less autonomous individuals. Hence,

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[405] Supra note 379, Chen (2016) 450-452. Chen argues that it is the diversity and extent of a choice or capability that should be the criteria for self-development which is pertinent to an 'open future'.

[406] Aliya O Affdal and Vardit Ravitsky, 'The Best Interest Standard and the Child's Right to an Open Future' (2018) 18 The American Journal of Bioethics 74, 75. Note, the authors are writing in the context of ovarian tissue cryopreservation where it involves existing individuals.

[407] See for instance, Erica K Salter, 'Deciding for A Child: A Comprehensive Analysis of the Best Interest Standard' (2012) 33 Theoretical Medicine and Bioethics 179 where the author offers three critiques against the best interest test: first, that it is not well-defined and has been inconsistently applied (in Salter's writing, in the context of paediatric decision making); second, that it is 'unreasonably demanding and narrow' in practice; and third, it falls short of treating and respecting the family as an unified whole.

it is doubtful if the open future can offer an adequate guiding principle in the context of HGE, particularly from the children's perspective.

- *Open Future Argument in the Heritable Genome Editing Context*

The open future argument appears tempting as a ground to justify the use of HGE for disease-related reproductive purposes. It is not against intuition to claim that children born healthy (compared to those born with serious genetic-related disorders) may have a more expansive future filled with more opportunities. Hammerstein and others are among those work that is in line with this thinking. They claim that HGE for the purpose of preventing severe genetic diseases 'will likely open many doors that would be closed otherwise'[408] and that disease and disorder (instead of HGE itself) 'presents the greatest threat to children's future autonomy'.[409] Mintz and others also observe that preventing pain and suffering may be an ethical use of HGE for it 'opens a child's future' which would otherwise be hindered by illness management.[410]

The notion of an open future is not only discussed in academia but also recognised in the regulatory consultation process. In particular, the UK Human Fertilisation and Embryology Authority ("HFEA") has considered this (in brief) when dealing with a procedure which technically is also a type of germline modification – the mitochondrial replacement technique (MRT). As introduced in Chapter 1, MRT involves alteration of DNA which is done on the mitochondrial genome and any changes done on the eggs will be passed on through the maternal line. In this instance, the HFEA explicitly advised the UK government to take into consideration whether 'modifying the germ line (would) affect a child's right to an open future', although the substance of "open future" in this context is not elaborated in the

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[408] Alix Lenia v. Hammerstein, Matthias Eggel and Nikola Biller-Andorno, 'Is Selecting Better Than Modifying? An Investigation of Arguments Against Germline Gene Editing as Compared to Preimplantation Genetic Diagnosis' (2019) 20 BMC Medical Ethics 1, 6 & 11.

[409] Ibid, 6 citing Christopher Gyngell, Thomas Douglas, and Julian Savulescu, 'The Ethics of Germline Gene Editing' (2017) 34 Journal of Applied Philosophy 498, 508.

[410] Rachel L Mintz, John D Loike and Ruth L Fischbach, 'Will CRISPR Germline Engineering Close the Door to an Open Future?' (2018) 25 Science and Engineering Ethics 1409, 1416.

advice.[411] Additionally, in 2018, the Nuffield Council on Bioethics (“Nuffield”), in determining the ethical acceptability of HGE for reproduction, considers, inter alia, the rights-in-trust for the prospective children in maximising the chance to self-fulfilment in its analysis regarding the welfare of the future person.[412] This reflects the language of the open future argument[413] and reinforces the need to further examine the open future argument specifically in the HGE context.

Before going further, there is a theoretical issue regarding the application of a “right” to an open future in the HGE context that must be clarified. As “rights” are designed for actual people, there arises a concern of whether a right to an open future can conceptually apply to potential (unborn) children since HGE involves genome modification of gametes and/or early human embryos. Wilkinson observes this issue and proposes the use of an open future *principle* instead of a *right* to an open future. He argues that an open future principle captures the idea that it is wrong to create a person whose future is ‘insufficiently open’ in relevant aspects and this ‘non-right based principle’ can be well-applied to the human embryos and even gametes.[414] Mintz and others also seem to have endorsed this concern when they argue for an extension of the open future argument to preconception cases to cover the unborn children (embryos and foetuses). In making their claim, Mintz and others opt for the phrase of open future *theory*.[415] I agree with the approach in avoiding using the term ‘right-based’ since my discussion inevitably involves the unborn children where ascribing rights, be it legal or moral, may be contested. Therefore, I continue this chapter with the phrase “open future argument” when it is related to preconception and preimplantation intervention.

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[411] Supra note 110, HFEA (2013) para 6.12.

[412] Supra note 146, Nuffield Council on Bioethics (2018) para 3.28.

[413] Ibid, para 3.30. Nuffield acknowledges the conceptual difficulties in relation to ‘openness’ of a child’s future options.

[414] Stephen Wilkinson, '‘Designer Babies’, Instrumentalization and the Child’s Right to an Open Future' in Nafsika Arhanassoulis (ed), *Philosophical Reflections on Medical Ethics* (Palgrave Macmillan 2005) 59.

[415] Supra note 410, Mintz, Loike and Fischbach (2018).

The limitations of open future argument

Although Feinberg's notion on the child's right to an open future is influential, it is not always well-accepted. In the previous section, I highlighted that Feinberg's "open future" falls short of acknowledging children as present beings, having present interests. In addition to this critique, I also showed that the notion of an open future is both conceptually and practically ambiguous – the interpretation of "open" and "closed" future is highly subjective; the implications from ensuring an "open" future on part of the parents are burdensome following a strong interpretation of open future; even if we accept a more moderate view of open future, it remains doubtful what the reasonable range of choices should be provided for the children; and there is no clear methodology given by Feinberg in determining an "open" future.

Within the context of HGE, these ambiguities engender significant issues. The subjectivity of "open future" leads to the outcome where both the proponents and opponents of HGE can offer equally strong arguments to argue respectively that the technology can both open and close the future. It may be helpful to illustrate the open future argument using the case of the world's first genetically edited babies, Lulu and Nana.[416] In the following, I demonstrate the discrepancy that stems from the open future argument in answering whether the use of HGE is ethically justifiable in that situation.

As discussed earlier, Hammerstein and others argue that the use of HGE for the prevention of debilitating genetic conditions will likely open many doors.[417] Accordingly, it may be argued that, prima facie and all other things considered, scientist He Jiankui ("scientist He") has acted in an ethically acceptable manner in modifying the genes of the twins prior to their birth in order to prevent human immunodeficiency virus ("HIV"), given that patients with HIV may contact life-threatening conditions. One can easily imagine a life with more options if one has a healthy immune system. Thus, at first sight, it seems justifiable to argue that

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[416] See Chapter 1 of this thesis for a revision of the story in relation to Lulu and Nana.

[417] See supra note 408, Hammerstein, Eggel and Biller-Andorno (2019) 11.

scientist He’s action led to a more open future for the resulting children by preventing them from contracting HIV.

Nevertheless, one may also rely on the open future argument to argue against scientist He’s action. First, it seems that HIV is a controversial case because HIV does not necessarily limit one’s autonomy (considering the available drugs now to ensure people with HIV a normal life)[418] and hence, it does not necessarily lead to a more closed future (and consequently, it does not justify He’s action). Second, as Mintz and others remind us, even if the genome editing technology opens the door to certain capacities, options, skills or preferences, it may potentially also shut the door to others.[419] When scientist He edited the genes so that the twins were born resistant to HIV, at the same time, he also potentially exposed the twins to other diseases, given that editing one part of the DNA may have adverse effects on the other parts.[420] Schmidt argues, in a slightly different perspective, that parents also act unethically if they make selections by shifting (rather than restricting) the range of futures their children may pursue.[421] If this line of reasoning were accepted, then it is arguable that scientist He (or the parents) has acted unethically because by deciding to have children resistant to HIV, they have shifted the kind of future where they may be exposed to other diseases. There is a shift of open future because when the twins are immune with HIV, they are also exposed to other diseases or the unforeseen side effects from the act of modification. The wrong of shifting, according to Schmidt, is that parents (or the relevant authority) excessively determine their children’s futures by imposing the parents’ (or the scientist’s) conceptions of the child’s future and displacing the child’s own development of his or her future.[422] In the case of HGE, the potential harm is more unknown compared

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[418] NHS, ‘Treatment: HIV and AIDS’ (2018) <https://www.nhs.uk/conditions/hiv-and-aids/treatment/> accessed 28 December 2020

[419] See supra note 410, Mintz, Loike and Fischbach (2018).

[420] Robert J Ihry and Others, ‘p53 Inhibits CRISPR-Cas9 Engineering in Human Pluripotent Stem Cells’ (2018) 24 Nature Medicine 939; see also Angela Chen, ‘Flawed DNA Editing of Alleged ‘Designer Babies’ May Have Put Their Health at Risk’ (*The Verge*, 29 November 2018)<https://www.theverge.com/2018/11/29/18116830/crispr-baby-he-jiankui-genetics-ethics-science-health-mutation> accessed 29 December 2020. (Note, however, this may be considered as part of the technical issues which can be resolved following the advance of science and technology).

[421] Supra note 380, Schmidt (2007).

[422] Ibid, 196.

to living with HIV because in the latter case, the risks and impacts of HIV are more identifiable and can be prevented by taking necessary actions. Hence, the kind (or seriousness) of genetic diseases or genetic-related conditions that are eligible for HGE should be clarified in the ethical discussion and the open future argument fails to do this. I will revisit this issue in Chapter 4 when I discuss the capability approach.

Furthermore, how one approaches the technology of HGE also leads to differing interpretation or positions on whether the future would be "open" or "closed". The proponents may focus on the likely *outcome* of HGE (e.g. to prevent certain genetic diseases) to argue that it has "opened" the future. In contrast, the opponents may focus on the *means* of HGE that is intervention prior to birth leading to irreversible outcomes thus "closing" the future of the children. The inconsistency such as this makes the overall evaluation on the ethical permissibility of HGE inadequate where the concept of open future is adopted.[423] This again raises doubt in the open future argument's utility and efficiency as an ethical guiding tool in decision making relating to HGE.

The ambiguity has other significant implications in the HGE context. Should HGE be safe and effective for clinical use in the future, it is presumed that it is less controversial in determining its application to those genetic diseases where the effects are debilitating and life-limiting, and where the sufferer will die within a few years or even months after birth (e.g. Tay-Sachs disease – a fatal genetic disease affecting the nervous system of the babies/children).[424] In these cases, there is less doubt that the open future argument offers solid ground in allowing HGE in reproduction. What is more controversial is its use on those genetic conditions that bring no life-threatening implications, such as, genetic-caused deafness whereby one may live a life span as do hearing people except that he or she may face difficulties in hearing and carrying out hearing-related tasks in daily life. Following the open future argument, in such cases, it is not clear if it is ethically acceptable for parents (or government) to employ HGE in order to eliminate or prevent deafness of the

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[423] Jenny Krutzinna, 'Beyond an Open Future' (2017) 26 Cambridge Quarterly of Healthcare Ethics 313. The author makes this observation, albeit in a different context of paediatric cognitive enhancement.

[424] National Human Genome Research Institute, 'Learning about Tay-Sachs Disease' <https://www.genome.gov/10001220/learning-about-taysachs-disease/> accessed 29 December 2020.

child. On the one hand, as highlighted before in Davis' argument, it may be claimed that deliberately choosing a child with genetic deafness would violate the open future principle because the child is confined to narrower options.[425] This is in contrast with what Mintz and others note – individuals living with genetic conditions need not be living a more closed future as they similarly have their 'capacities, skills, options and preferences' albeit quite different from the one without any genetic conditions.[426] From this understanding, it is arguable that no one needs to have a totally open future with unlimited options to be regarded as autonomous (if autonomy is an important value attached to the open future notion). Given that the concept of open future can support both of these interpretations in how HGE should apply to genetically caused deafness, it does not seem to be able to provide clear guidance on grey areas such as this. What is also less clear is the cases of late-onset diseases such as Alzheimer's and Huntington's disease. It is hard to predict the openness of the future of the affected individuals.[427] One may argue that the future is closed because of contracting the disease but another may argue that the future is still open as long as they live a good life before the symptoms develop.[428]

Building upon the above discussion, I argue that the concept of an open future is not adequate in guiding the decision making concerning the reproductive use of HGE. This is due to the conceptual vagueness and practical challenges on the open future argument: it is unclear on how we should interpret an "open", a "closed" future, or a future with a "reasonable" range of choices; and ensuring an "open" future would exert undesirable burdens on the governments and on parents. These ambiguities leave the related parties (or the courts if it were open to legal challenge) to decide what amounts to "open" and "closed" future. Scientist He's affair, which results in the birth of genetically edited twins, provides a good illustration of how the concept of open future falls short of determining the ethical acceptability of his action (assuming that the technical and safety issues are resolved and there is no regulatory

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[425] Supra note 375, Davis (1997).

[426] Supra note 410, Mintz, Loike and Fischbach (2018) 1420.

[427] Ibid, 1422. (Note, in my thesis, "children" is also seen with the status as the offspring of their parents in addition to merely a particular age group or life stage; hence "children" born with late-onset diseases fall within my consideration, even when the symptoms or conditions may only occur when they reach adulthood.)

[428] Laura Purdy, 'Genetics and Reproductive Risks: Can Having Children be Immoral?' in Craig Hanks (ed), *Technology and Values: Essential Readings* (Wiley-Blackwell 2010) 458.

misconduct). Additionally, the ambiguity of the open future also makes it less applicable in decision making in grey areas such as genetic deafness and other late-onset diseases. Hence, I argue that the language of an "open future" should be avoided in considering the ethical acceptability of the use of HGE. Nonetheless, I acknowledge the value that the open future argument seeks to protect, i.e., the (future) autonomy of the children. However, as distinct from Feinberg's, what concerns me is not merely the future adult he/she will grow into, but also the child's experiences during childhood. I argue that there is a need for a solid philosophical and theoretical framework to capture children's developing autonomy. As I further argue in Chapter 4, the capacities (or more accurately, capabilities) for autonomy should be the key in the ethico-legal evaluation of certain decisions and a capability approach is able to capture this. Before that, I now explore another issue of whether there is a right to a non-modified genome for future children.

3.1.3 Is there a right to a genuine "genetic identity" for future people? [429]

The right to untampered genes and/or genomes[430] has been frequently raised in the academic literature as an opposing argument against the use of HGE. Still, such a notion is one that is the least analysed.[431] This notion arguably stemmed from the recommendation made by the Parliamentary Assembly of the Council of Europe[432] ("PA") in 1982 where, in relation to genetic engineering, the PA recommended that there might be a 'right to inherit a genetic pattern which has not been artificially

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[429] Parts of section 3.1.3 have been included in Ying-Qi Liaw, Ilke Turkmendag and Kathryn Hollingsworth, 'Reinterpreting "Genetic Identity" in the Ethical and Regulatory Context of Heritable Genome Editing' (2021) New Genetics and Society 1.

[430] For a revision of the meaning of "genes" and "genomes", see Chapter 1, section 1.1.1 of this thesis.

[431] See for instance, Nils Holtug, 'Identity, Integrity, and Nuclei Transplantation' (1998) 17 Politics and the Life Sciences 20. This idea is also raised (very briefly) in Francoise Baylis, 'The Ethics of Creating Children with Three Genetic Parents' (2013) 26 Reproductive BioMedicine Online 531, 534. Kathleen Nolan, 'Commentary: How Do We Think about the Ethics of Human Germ-Line Genetic Therapy?' (1991) 16 The Journal of Medicine and Philosophy 613, 614.

[432] The Parliamentary Assembly (PA) is the 'deliberative body and the driving force of the Council of Europe', to which parliamentarians are selected by the domestic parliaments of 47 member states of the Assembly, see UK Parliament, 'Parliamentary Assembly of the Council of Europe' <https://www.parliament.uk/mps-lords-and-offices/offices/delegations/coe2/> accessed 25 November 2020. The PA is not an European institution and it is believed that after Brexit, the UK can still participate in the discussion by the body, see Kerry Mccarthy, 'After Brexit, the Council of Europe Will Only Become More Important' (*The New European News*, 17 September 2020) <https://www.theneweuropean.co.uk/brexit-news/kerry-mccarthy-after-brexit-the-council-of-europe-will-only-69870> accessed 25 November 2020.

changed'.[433] According to the 1982 recommendation, such a right may be derived from the right to life and human dignity enshrined in the European Convention on Human Rights.[434] The claim for a non-modified genome connotes the idea that there should be a *genuine* "genetic identity",[435] where "genuine" means without any intentional interference; hence, the human genome should not be intentionally manipulated (for example, via HGE). This view engenders a narrow interpretation whereby it only includes germline modification targeted at germ cells or early human embryos but excludes accidental germline effects from somatic genome editing.[436] In such a context, it is arguable that "children" are protected *collectively* by focusing on a purported right to untampered genes and/or genomes. For instance, in the context of modification of the mitochondrial genome, it has been suggested that there is a possible right for the *future generations* to inherit an 'un-manipulated genome', whether it is for enhancement or therapeutic purposes.[437] Also, as proposed by the Council for Genetic Responsibility, 'all people have the right to have been conceived, gestated and born without genetic manipulation'.[438] All these suggest that there may indeed be an interest in having a genuine genetic identity, rendering this issue essential for further examination.

The main task in this section is to examine how "genetic identity" has been conceptualised in the current international provisions because it influences our attitudes towards the ethical acceptability of HGE and it also has implications in the regulations of HGE (e.g. whether a restrictive or permissive approach should be taken). This section first explores the possible grounds for the purported right to an a genuine "genetic identity" (i.e., an untampered genome) derived from the UNESCO's Universal Declaration on the Human Genome and Human Rights 1997

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[433] Parliamentary Assembly, 'Recommendation 934: Genetic Engineering' (1982) <https://assembly.coe.int/nw/xml/XRef/Xref-XML2HTML-en.asp?fileid=14968&lang=en> accessed 28 December 2020, para 4(a).

[434] Ibid, para 4(a).

[435] What amounts to "genetic identity" in this context will be elaborated shortly.

[436] Erik Parens, 'Should We Hold the (Germ) Line?' (1995) 23 Journal of Law, Medicine and Ethics 173, 175.

[437] Supra note 153, Baylis and Robert (2006).

[438] The Board of Directors, Council for Responsible Genetics, 'The Genetic Bill of Rights' (April 2000) <https://www.iatp.org/sites/default/files/Genetic_Bill_of_Rights_The.htm> accessed 29 December 2020, Art 10.

("1997 Declaration"), focusing on the common heritage view and the concept of human dignity. I show that the rationale underpinning this purported right as implied by the current international regulations is unsatisfactory in justifying such a right and/or interest. Following this, a right or an interest to a genuine "genetic identity" is unlikely to be plausibly established, but as I suggest, the common heritage view and the concept of human dignity can at least exert some level of precaution towards the use of HGE. In the last part of this section, I also show that it is the human (species) identity that international law intends to protect for the sake of future children.

Before examining the related international provisions, it is crucial to clarify two issues at the outset. First, as the right to an untampered genome is putatively a right for future individuals, it raises the question whether future people can ever have rights. It is worth first clarifying that just as there is a conceptual problem in claiming a "right" to an open future in the HGE context, claiming a "right" to an untampered genome may face the same conceptual difficulty – that is, whether future children can have "rights". Although it may be argued that such rights will only crystallise upon birth,[439] I avoid using the right-based term in the following writing as well for the sake of consistency. Thus, this section proceeds with the word "interest" – an interest not to have genes and/or genomes tampered with before birth (I will, however, use the word "right" where its use is explicit in the current legal provisions). It is also worth noting that the question as to whether future generations can have "rights" is not unique to the HGE debate;[440] thus, I do not include this discussion in this thesis. Second, it has also been questioned whether the "right" can ever be violated if the only way for the resulting child to exist is by means of the genetic modification prior to birth.[441] This question relates closely to the non-identity problem discussed earlier (see section 3.1.1 of this chapter). As I argued earlier, the non-identity problem should not be the only focus when taking a child-centred approach in the HGE debate, but also of concern are the interests of the

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[439] Supra note 414, Wilkinson (2005) 59.

[440] For instance, this issue is commonly discussed in the context of environmental policy intervention (see e.g. Edith Brown Weiss, 'Our Rights and Obligations to Future Generations for the Environment' (1990) 84 The American Journal of International Law 198).

[441] See supra note 431, Holtug (1998).

prospective children who would actually exist due to this procedure. It is, therefore, not the aim of this section to revisit the non-identity problem here.

Based on the current international provisions, the interest not to have genes tampered with before birth appears to be founded on two possible grounds: (1) that human genomes should be protected because they are the common heritage of humankind; and/or (2) the intentional alteration of human genomes is contrary to human dignity. This is seen in the 1997 Declaration – the first international legal and ethical framework to regulate the activities relating to the human genome – where, in the first Article, it declares that 'the human genome underlies the fundamental unity of all members of the human family, as well as the recognition of their *inherent dignity* and diversity. In a symbolic sense, it is the *heritage of humanity*'.

- Human genome as the "common heritage of humanity"

Reading the Article by itself, it is unclear what it means to view the human genome as a common heritage of humanity. Referring to Emmanuel Agius' work, it is arguable that the human genetic system is part of the common heritage of humankind due to the heritable effects of genes in which the genes are passed down from one generation to the other.[442] This genetic heritage belongs to all human beings and the collective human gene pool goes beyond 'national or temporal boundaries' and is 'the biological heritage of the entire human species'.[443] This explains the claim of a possible right to an untampered genome in a collective sense. Nonetheless, the applicability of the common heritage view to human genomes is not without dispute. From a scientific perspective, the view of common heritage is conceptually problematic. As Juengst points out, first, there is no 'germline' in human species in the genealogical sense[444] and second, the human genome is an abstraction, a formal

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[442] Emmanuel Agius, 'Patenting Life: Our Responsibilities to Present and Future Generations' in Emmanuel Agius and Salvino Busuttil (eds), *Germ-Line Intervention and Our Responsibilities to Future Generations* (Kluwer Academic Publishers 1998) 75.

[443] Ibid, 76.

[444] Eric Juengst, 'Should We Treat the Human Germ-Line as A Global Human Resource?' in Emmanuel Agius and Salvino Busuttil (eds), *Germ-Line Intervention and Our Responsibilities to Future Generations* (Kluwer Academic Publishers 1998) 87. 'Germline', as Juengst explains, ends in an organism's reproductive cells since germline technically means the lineage of dividing cells within an organism that link its embryonic stage with its fully differentiated reproductive cells.

scientific concept and not a natural resource.[445] Similarly, as Resnik explains, it is hard to identify one single 'thing' as the human genome because of the idea of genetic variations in which every individual owns a different set of genes.[446]

Even if we set aside the scientific viewpoint, applying the concept of common heritage to the human genome, particularly to the context of HGE, creates other issues. It is pointed out that the idea of the 'common heritage of humankind' was first developed within a different context in relation to the international sea and outer space.[447] The common heritage idea in such contexts deals *not* with ownership but the uses of the designated area for the good of humankind, to serve the common interest of people everywhere.[448] While this non-appropriation principle seems more applicable (but also not without controversy) to the issue concerning patenting the human genome (it is thought that if the human genome is a common heritage, then no patent on genome-related products should be permissible),[449] it is not entirely clear if this principle can be applied to the legality or ethical acceptability of germline editing. Primc observes that the common heritage idea does not provide an answer to the ethical permissibility of germline modification[450] if it is interpreted as giving the people or nations equal property interests in a territory or resource.[451] In a similar vein, Hey also opines that the common heritage of humankind which aims to serve human interests 'resounds with discourse that addresses how benefits and burdens are to be shared from beneficial uses of the human genome and human genetic databases' but, it does not fit with other concerns, such as what it means to

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[445] Ibid, 89. Juengst defines 'human genome' as the 'full set of genetic loci that characterises our species, together with the structural (noncoding) elements that connect them'.

[446] David Resnik, 'The Human Genome: Common Resource but not Common Heritage' (2005) 5 Frontis 197, 200.

[447] Nadia Primc, 'Do We Have A Right to An Unmanipulated Genome? The Human Genome as the Common Heritage of Mankind' (2020) 34 Bioethics 41, 42.

[448] Carol Buxton, 'Property in Outer Space: The Common Heritage of Mankind Principle vs. the First in Time, First in Right, Rule of Property' (2004) 69 Journal of Air Law and Commerce 689, 692.

[449] See for example, Barbara Looney, 'Should Genes Be Patented? The Gene Patenting Controversy: Legal, Ethical, and Policy Foundations of an International Agreement' (1994) 26 Law and Policy in International Business 231; Melissa Sturges, 'Who Should Hold Property Rights to the Human Genome? An Application of the Common Heritage of Mankind' (1999) 13 American University International Law Review 219.

[450] Supra note 447, Primc (2020) 43.

[451] Pilar Ossorio, 'The Human Genome as Common Heritage: Common Sense or Legal Nonsense?' (2007) 35 Journal of Law, Medicine & Ethics 425, 427 & 428.

be human in a collective sense.[452] The latter seems to be a more relevant concern, or even fundamental to the HGE debate, especially dealing with the question of the morality of HGE.

Therefore, instead of focusing on the property rights, some scholars including Ossorio point to a so-called 'common heritage *duties* doctrine' in which it 'articulates a special interest of all people in certain cultural or natural objects and a duty to help preserve them'.[453] Primc argues that this understanding is a more promising one for the opponents of germline manipulation because it implies a duty to preserve the human genome.[454] This duty, if understood with the right to an unaltered genome, stipulates that there should be no intervention on the human genome by any technical concerns.[455] Unfortunately, further problems remain with the 'duty to preserve human genome'.

First, the idea of "protection of human genome" is problematic as it connotes genetic determinism (that we are determined by our genes) – a notion which has consistently been rejected by the Legal Commission of the International Bioethics Committee of UNESCO (the Committee)[456] and eventually included a provision to condemn the notion of genetic determinism in the 1997 Declaration.[457] In the preparatory work of the 1997 Declaration, it is also emphasised that a right to respect one's genetic

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[452] Ellen Hey, 'Interdependencies, Conceptualizations of Humanity and Regulatory Regimes' in Britta van Beers, Luigi Corrias and Wouter Werner (eds), *Humanity Across International Law and Biolaw* (Cambridge University Press 2014) 264.

[453] Supra note 451, Ossorio (2007) 430.

[454] Supra note 447, Primc (2020) 44.

[455] Ibid. Note, a duty to preserve human genome does not necessarily lead to a right to an unaltered genome. In fact, there is claim that HGE is needed for the very same purpose of preserving human (species) genome. For instance, Powell takes on an evolutionary perspective and argues that germline intervention to correct mutations that bring about debilitating disorders may be needed to preserve the quality of human gene pool 'in light of the relaxation of selection pressures due to the increasing effectiveness and availability of conventional medicine.' (see Russell Powell, 'In Genes We Trust: Germline Engineering, Eugenics and the Future of the Human Genome' (2015) 40 Journal of Medicine and Philosophy 669, 673-679 & 680-682). In making such a claim, the author also defends that his view does not equate to the old eugenics in the sense that his argument merely focuses on hereditary diseases and he does not conflate 'the undesirability of certain genes with the moral worth of the people who carried them'. (see Powell (2015) 684.)

[456] Division of the Ethics of Science and Technology of UNESCO, 'Birth of the Universal Declaration on the Human Genome and Human Rights' (1999) <http://unesdoc.unesco.org/images/0011/001193/119390eo.pdf> accessed 26 December 2020, 3, 62, 68, 75.

[457] The Universal Declaration on the Human Genome and Human Rights 1997, Article 3.

heritage (that is not to be discriminated against) should not be seen as equivalent to the inviolability of human genome.[458] The sanctity of human genome is rejected on a consistent basis in the process.[459] The Committee clarifies that the purpose of the Declaration is to 'ensure the protection of the human genome against all forms of experimentation or use that are incompatible with respect for human dignity, a fundamental principle of bioethics' and that 'the purpose of protecting the human genome is to safeguard the integrity of the human species'.[460] All these suggest that a duty to preserve human genome need not lead to an outright ban on HGE, as long as it is used in accordance with "respect for human dignity" and "integrity of the human species" (discussed more later).

Second, if the duty to preserve the human genome is based on safety concerns, arguably then a right to an untampered genome is only a provisional right because it can only sustain until the safety concern is resolved.[461] The Committee clearly stated, in the preparatory process of the 1997 Declaration, that the prohibition on germline editing at the time of drafting the declaration is due to the state of scientific knowledge at that time.[462] This is also demonstrated in the Oviedo Convention which allows amendment of the provisions (Article 32). Indeed, the closest provision to the alleged right/interest to have untampered genomes may be the current standing of Article 13 of the Oviedo Convention which explicitly restricts any germline intervention with the purpose of changing the genome of descendants. However, the position is arguably flexible and adapted to the current state of technologies because, as UNESCO in its 2017 recommendation reminded us, such a position may be subject to change after a robust public debate on the fundamental ethical, legal and social issues.[463] Consequently, an interest to have a non-modified genome is at best merely temporary and can be lifted when the technology is proven safe and effective enough. While this may be seen in line with children's interests,

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[458] Supra note 456, Division of the Ethics of Science and Technology of UNESCO (1999) 71.

[459] Ibid, 62, 66, 68.

[460] Ibid, 62.

[461] Supra note 447, Primc (2020) 44.

[462] Supra note 456, Division of the Ethics of Science and Technology of UNESCO (1999) 62.

[463] Ibid, para 3. For the provision regarding public debate, see Art 28 of the Oviedo Convention.

it is also suggested that if safety of the technology is the concern, we need not rely on the common heritage view (with a duty to preserve human genome) to prevent harm to future generations in the context of HGE.[464]

Third, the support in favour of this right is not as strong as first claimed in 1982, hence it continues to leave such a duty to preserve the human genome vague or even redundant. It is notable that even when the PA suggested the ‘right to inherit a genetic pattern which has not been artificially changed’ be included as part of human rights back in 1982, this alleged right has not been included in the human rights provisions to date. There is also an exception to the recommended right – that is when the use of genetic engineering is for therapeutic purpose with great promise to treat and *eradicate* certain genetic diseases.[465] Some authors suggest that the use of germline editing for “eradicating” genetic diseases may fall under this exception.[466] Although HGE remains ethically questionable following the 2017 recommendation,[467] the fact that the PA does not include or reemphasise the right to inherit an unmanipulated genome in its more recent recommendation suggests a changing attitude towards this right (and thus, towards a duty to preserve human genome).

Hence, even if it is agreed that human genome is a common heritage, it is questionable whether this view would constitute a right/an interest to an untampered genome. One possible remedy for this situation is to adopt what Resnik has suggested, albeit in a patenting human genome context, that there should be a symbolic interpretation (instead of literal interpretation) of the common heritage.[468] UNESCO itself has stressed this symbolic sense in the first Article. Referring to the preparatory work, it may be emphasised that the purpose of including the idea that

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[464] Supra note 447, Primc (2020) 44.

[465] Supra note 433, Parliamentary Assembly (1982) para 4(c).

[466] Rosamund Scott and Stephen Wilkinson, ‘Germline Genetic Modification and Identity: The Mitochondrial and Nuclear Genomes’ (2017) 37 Oxford Journal of Legal Studies 886.

[467] Parliamentary Assembly, ‘Recommendation 2115: The Use of New Genetic Technologies in Human Beings’ (2017) <https://assembly.coe.int/nw/xml/XRef/Xref-XML2HTML-en.asp?fileid=24228&lang=en> accessed 26 December 2020, para 3. The PA came up with another recommendation stating that ‘deliberate germ-line editing in human beings would cross a line viewed as ethically inviolable’.

[468] Supra note 446, Resnik (2005).

human genome is a common heritage as a symbolic sense is not to completely prohibit HGE but ‘to underline the fact that research on the human genome and the applications that flow therefrom entail the responsibility of humanity as a whole, in the interest of present and future generations’.[469] Therefore, it can be concluded that genome editing, including HGE deserves high precaution in regard to its clinical implementation and has to be examined on its own merits to determine its legality and morality.

- *Human genome and human dignity*

Another possible way to defend an interest to have unaltered genomes is through the concept of human dignity. Article 24 of the 1997 Declaration indicates that germline (that is, heritable) genetic intervention is a practice that *could be* contrary to human dignity. This suggests that attempts to intervene the germ cells may, but not necessarily, be considered as contrary to human dignity. Agreeing to this, Krekora-Zajac points out that the position implied by Article 24 is different from Article 11 which clearly forbids the act of reproductive cloning on the ground that it is contrary to human dignity.[470] Hence, it is argued that the wording of the 1997 Declaration suggests that certain form of genetic intervention prior to birth may be acceptable and need not be a threat to human dignity or humanity.[471]

Before going further, the applicability of the concept of human dignity in the HGE debate must be clear. Since the language of rights cannot readily be used to deal with concerns relating to future generations or humanity at large, Andorno explains that the concept of human dignity may then provide a theoretical ground to prevent misuse of technology when it comes to protection of future generations or humankind.[472] Following this, the concept of human dignity seems applicable to the context of HGE which inevitably involves future people. Nevertheless, how the

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[469] Supra note 456, Division of the Ethics of Science and Technology of UNESCO (1999) 3.

[470] Dorota Krekora-Zajac, ‘Civil Liability for Damages Related to Germline and Embryo Editing against the Legal Admissibility of Gene Editing’ (2020) 6 Palgrave Communications 1, 3.

[471] Ibid, 3.

[472] Roberto Andorno, ’Human Dignity and Human Rights as A Common Ground for Global Bioethics’ (2009) 34 Journal of Medicine and Philosophy 223.

concept should be interpreted in the context of HGE remains ambiguous. Arguably, dignity, from the international perspective of protection of human species, is seen as something that is inherent to human beings. Fukuyama argues that respect for human dignity indicates that there are some fundamental human qualities 'worthy of a certain minimum level of respect' when we eliminate all the contingent characteristics of ours.[473] In line with this notion, Andorno also suggests that when dignity is deemed intrinsic, then it is not an 'accidental quality of some human beings' but rather 'an unconditional worth that everyone possesses by virtue of being human'.[474] If we agree on the intrinsic value of dignity, the concept of human dignity, understood in this way, cannot ground the possible right of an untampered genome because it would imply that those born as a result of such technique are somehow less "dignified" (or afforded less dignity) than those who are not; dignity is, after all an unconditional worth to which all humans (including those born via HGE) are entitled.

Nonetheless, the concept of human dignity continues to gain traction in the HGE debate. In the updated statement by UNESCO in 2015, it is stated that HGE would 'jeopardise the inherent and therefore equal dignity of all human beings'.[475] This statement seems to go against the view that every human being, including those born genetically modified before birth, should be treated as having the same dignity as any other human being. While it is tempting to abandon the concept of human dignity due to its vagueness,[476] I am more inclined towards Hayry's and Woods' reservation to dismiss such a concept.[477] One possible interpretation of the concept of human dignity which is more plausible, and very much in line with a child-centred approach, may be that HGE should only be carried out (if proven safe and effective) in a way

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[473] Francis Fukuyama, *Our Posthuman Future: Consequences of the Biotechnology Revolution* (Profile Book 2002) 149.

[474] Roberto Andorno, 'What is the Role of 'Human Nature' and 'Human Dignity' in Our Biotechnological Age?' (2011) 3 Amsterdam Law Forum 52.

[475] Supra note 247, International Bioethics Committee (2015).

[476] Ruth Macklin, 'Dignity is a Useless Concept' (2003) 327 British Medical Journal 1419.

[477] Matti Hayry, 'Another Look at Dignity' (2004) 13 Cambridge Quarterly of Healthcare Ethics 7; Simon Woods, 'Dignity: Yet Another Look' in Tuija Takala, Peter Herrisone-Kelly, Soren Holm (eds), *Cutting Through the Surface: Philosophical Approaches to Bioethics*. Brill Rodopi 2009) 69-80.

that does not involve instrumentalization of the resultant individuals.[478] Andorno rightly warns that people should not be treated as research tools and that scientific advancement is not an end in itself but merely a way to improve people's welfare.[479] Scientist He's affair (see Chapter 1) is, regrettably, a good illustration of such instrumentalization. In their hope for a breakthrough in the field of HGE and for fame and profit,[480] scientist He and his team seem to have disregarded the primacy of interests and welfare of resulting individuals born via the premature procedure. It is thus arguable that they fail to demonstrate respect for human dignity in such instance. The concept of human dignity if interpreted in this way seems to have a more substantive and feasible place in the current context of HGE.

The discussion so far suggests that perceiving the human genome as common heritage does not plausibly lead to a protected interest of a genuine "genetic identity" before birth, but it calls for heightened consideration in the use of HGE in humans since the human genome in its symbolic sense, represents the whole of humanity. It seems that the preferable outcome derived from observing the human genome as part of common heritage is not a claim for a right to an untampered genome, but – as has been frequently raised in the existing debate – that there should be a robust and *inclusive* public deliberation on the complex ethical and socio-legal issues before any clinical implementation of HGE.[481] Similarly, the concept of human dignity also does not indicate an interest of unaltered genome for the future children. However, this does not mean that the concept should be abandoned. I observed that there is a fundamental version of dignity that can help us determine which use of HGE should not be allowed (that is, those applications that tend to instrumentalize the research subjects).

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[478] Kristof Van Assche and Sigrid Sterckx, 'The Protection of Human Dignity in Research Involving Human Body Material' in Britta Van Beers, Luigi Corrias and Wouter Werner (eds), *Humanity Across International Law and Biolaw* (Cambridge University Press 2014) 278. The authors suggest that 'the requirement of non-instrumentalization is a direct corollary of the principle of respect for human dignity'.

[479] Supra note 472, Andorno (2009) 228.

[480] Supra note 4, Greely (2019) 142.

[481] For a discussion of the importance of having a public discourse in the genome editing debate, see for instance, Alessandro Blasimme, 'Why Include the Public in Genome Editing Governance Deliberation' (2019) 21 AMA Journal of Ethics E1065.

Therefore, as with the open future debate, there is *some* utility in framing the human genome as common heritage of humanity and with the concept of human dignity in the context of HGE, albeit the utility is not in the form of a right to an untampered genome (i.e., a right to a genuine "genetic identity"). I now briefly consider what amounts to a protection of "genetic identity" since it is one of the key interests which underpins the current prohibition in international law of germline modification.[482]

- Protection of "species identity"

If a "right" to a genuine genetic identity is not plausible following the grounds underpinning the current international provisions, the question then is whether there is a kind of "genetic identity" that international law intends to protect for the sake of future children. Looking at the preparatory and drafting process of the 1997 Declaration, it may be arguable that the "identity" in mind is of human identity (or species identity). This is because the need to protect and safeguard the integrity of "human species" was widely adopted in the earlier drafts of the 1997 Declaration[483] (notwithstanding that the phrase was substituted with "human family"[484] in the final version). The intention to protect the human species is also acknowledged in the explanatory report of the Oviedo Convention although it similarly expresses its intention to respect individual's interest. In particular, it is explained that Article 13 of the Oviedo Convention is to answer the 'fear of intentional modification of the human genome so as to produce individuals or entire groups endowed with particular characteristics and required qualities'.[485] In its preparatory work on the Oviedo Convention, the Working Party also noted that the term "identity" of the human being covers both 'membership of the human species (so ruling out hybrids) and the

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[482] Helena Boussard, 'Individual Human Rights in Genetic Research: Blurring the Line between Collective and Individual Interests' in Therese Murphy (ed), *New technologies and Human Rights* (Oxford University Press 2009) 246-271.

[483] Supra note 456, Division of the Ethics of Science and Technology of UNESCO (1999) 118, 122, 126, 131.

[484] The Universal Declaration on the Human Genome and Human Rights 1997, Article 1.

[485] Council of Europe, 'Explanatory Report to the Convention on Human Rights and Biomedicine' (1997) <https://rm.coe.int/16800ccde5> accessed 29 December 2020, para 89.

individual's genetic identity'.[486] Although both collective and individual interests are emphasised in the Convention, it seems that what is protected under Article 13 is a collective interest of not having tampered genomes prior to birth.

The above discussion suggests that it is unlikely that the future children have a legitimate claim for an interest of not having tampered genome. It is neither scientifically plausible, nor can adequate justification be found in the current international instrument. It is also not clear if protection of this kind of "genetic identity" is adequate in safeguarding future children in the context of HGE. Thus, the discussion here points us to the ambiguity on the concept of "genetic identity" in the overall HGE debate, and the need to further explore what kind of "identity" that should be protected in light of children's interests. Although this thesis is not able to cover all possible interpretations of "genetic identity" relating to genetic knowledge,[487] it aims to first look at the concepts of "identity" relevant to the HGE debate (Chapter 5) and further explore another conceptualisation of "genetic identity" – that is as "genetic origins" – and their implications to the debate on HGE (Chapter 6).

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So far, sections 3.1.1-3.1.3 focus on how children have been positioned within current HGE debates. Section 3.1.1 considered the non-identity problem which highlights the dilemma to explain the moral wrong for certain decision which would eventually lead to the existence of an individual. If we accept the non-identity problem, then in principle, children cannot, in most cases, be harmed by a choice relating to HGE. Section 3.1.2 examined the right to an open future where it emphasises that children should be given a range of opportunities, providing them

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[486] Steering Committee on Bioethics, 'Preparatory work on the Convention on Human Rights and Biomedicine' (2000) <https://www.coe.int/t/dg3/healthbioethic/texts_and_documents/CDBI-INF(2000)1PrepConv.pdf> accessed 29 December 2020, 10. The protection of "genetic identity" may signify different thing when it is interpreted from either a collective view or an individualistic view. De Andrade criticises the emphasis that the current international legal framework has put on the collective interests and which thus overlooks the individual beneficial interest of being genetically modified. (see Norberto Nuno Gomes de Andrade, 'Human Genetic Manipulation and the Right to Identity: The Contradictions of Human Rights Law in Regulating the Human Genome' (2010) 7 Scripted 429). If it is established that the international instrument protects both individual and collective interests when it comes to genome modification, there is then a concern as to how to balance those individual interests with the collective ones.

[487] Floor M Goekoop and Others, 'Systematic Scoping Review of the Concept of Genetic Identity and Its Relevance for Germline Modification' (2020) 15 PLoS ONE 1.

with an “open” future. Following this, HGE should, arguably, only be used in a way that does not restrict at all or shift the future of prospective children. Section 3.1.3 discussed the purported right to a genuine “genetic identity” in which it claims that future children should not be intentionally genetically modified prior to birth. If successfully established, it leads to the position that no HGE should be used for reproductive purpose. I have argued that each of these issues are inadequate from a child’s perspective as to answer whether and how HGE should be used (a summary of this will be given in the conclusion of this chapter) but that each paves the way to the discussions in my next few chapters (e.g. the non-identity problem which merely focuses on “numerical” identity flags the need to explore other concepts of “identity” as well as the need to reconsider what would amount to “harm” to the resulting children in the application of HGE; the open future argument stresses future opportunities for the children which needs more refinement to better capture the *capabilities* for autonomy; and the right to a genuine “genetic identity” also flags the need for clarifications on the concept of “identity” in general and more specifically “genetic identity” in the context of HGE). Before setting out an alternative theoretical framework for the regulation of HGE from a child-centred perspective (one based on a capability approach and identity), I turn in this section to consider the position of children *if and when* HGE is allowed. Given the speed of technological advance in the field of genome editing, this is also a pertinent issue relating to children in the current debate so as to ensure that there is effective measures or policies available to protect the prospective children’s interests.

3.1.4 A long-term monitoring plan to safeguard prospective children’s interests?

If HGE is allowed for reproductive purposes, there is a need to consider the resulting children who are born via this procedure. Consider the twins (Lulu and Nana) born genetically modified in China – what can we do to protect their interests? In this section, I consider the available proposals in the current debate, one of which is to have a long-term monitoring plan.[488] While this type of proposal appears laudable and indeed much needed, it overlooks the fact that in order to carry out that long-

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[488] Supra note 56, NAS (2020) Recommendation 6; ‘Statement by the Organizing Committee of the Second International Summit on Human Genome Editing’ (*The National Academics of Sciences, Engineering and Medicine* November 29, 2018) <http://www8.nationalacademies.org/onpinews/newsitem.aspx?RecordID=11282018b> accessed 26 December 2020; also see supra note 2, NASEM (2017) 123.

term monitoring plan, the child must be given information about their origins. As I show, this proposal therefore currently appears weak and insufficient to properly safeguard the resulting children's interests. This is because there is no robust conceptual basis to explain why monitoring is important and how it might be effectively implemented in the future. I propose that this gap can be closed by understanding the need for accurate and truthful information, which in the context of HGE, is the fact about being born genetically modified.

There are currently several recommendations for how a responsible clinical trial of HGE should be conducted. Besides requirements such as having an independent oversight body, that no other reasonable alternatives to HGE are available, and its clinical use is restricted to cases of compelling medical need,[489] one commonly raised proposal is to have a long-term monitoring mechanism.[490] This proposed long-term follow up includes multigenerational monitoring of both the resulting children (from the original clinical applications) and their descendants.[491] It is justified based on the potential health risks to the resulting children and the next generations (given that the side effects of genome editing may manifest only decades later).[492] This long-term requirement is deemed necessary to better evaluate the success rate and safety of the techniques.[493] Thus, such a long-term follow up is crucial as a form of risk reduction for children, be it the immediate or distant future children.[494]

However, the idea of subjecting children to lifelong monitoring can seem ethically unacceptable. Cwik points out that intergenerational follow up would expose the descendants of the original families who employed HGE to 'potential abuse,

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[489] Ibid, 'Statement by the Organizing Committee of the Second International Summit on Human Genome Editing' (2018).

[490] Ibid; also see supra note 2, NASEM (2017) 123.

[491] Bryan Cwik, 'Designing Ethical Trials of Germline Gene Editing' (2017) 377 The New England Journal of Medicine 1911, 1911-1912; also see supra note 2, NASEM (2017) 8 & 12.

[492] Guido de Wert and Others, 'Responsible Innovation in Human Germline Gene Editing. Background Document to the Recommendations of ESHG and ESHRE' (2018) 26 Human Reproduction Open 250.

[493] Supra note 491, Cwik (2017) 1912.

[494] Supra note 492, de Wert and Others (2018).

exploitation, and psychological harms'.[495] But, considering the potential benefit, e.g. to eliminate particular genetic conditions from the family lineage that can be achieved via the use of HGE, and the uncertain risks from its use, it is then arguable that this long-term monitoring system is ethically justifiable.[496]

Even if we accept that this multigenerational follow up mechanism is ethically appropriate (and ethically required), the steps to implement such a long-term follow up remain vague.[497] As recognised by de Wert and others, there are practical limitations, including the possible tension with parental autonomy and family privacy as well as children's (individuals') privacy.[498] Baylis, who similarly expresses concerns about not having to compel parents to participate in such a programme and that "children" are free to decide upon whether to be monitored reaching the age of maturity, also questions how a "sufficient" plan for long-term monitoring of children should be determined in this context.[499] Acknowledging that it may not be possible to force parents or children to enrol on a plan which may last a lifetime, the National Academies of Sciences, Engineering, and Medicine (NASEM) suggests that 'encouragement is permitted' in such instance.[500] Accordingly, the proposal for long-term monitoring remains weak and the protection of children's interests is only minimal.

I argue that there is a lack of substance in the "long-term follow up" recommendation currently made.[501] More specifically, I observe that what has been

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[495] Supra note 491, Cwik (2017) 1912.

[496] Ibid, 1913. Cwik however acknowledges that finding a balance between the potential benefits and risks can be challenging.

[497] Heidi C Howard and Others, 'One Small Edit for Humans, One Giant Edit for Humankind? Points and Questions to Consider for A Responsible Way Forward for Gene Editing in Humans' (2018) 26 European Journal of Human Genetics 1, 4.

[498] Supra note 492, de Wert and Others (2018).

[499] See supra note 314, Baylis (2019).

[500] Supra note 2, NASEM (2017) 123.

[501] In this thesis, I do not question whether long-term monitoring is ethically appropriate for the immediate children or subsequent generations and I do not consider what amounts to a comprehensive long-term monitoring mechanism. see Charis Thompson, 'How Should "CRISPRed" Babies Be Monitored Over Their Life Course to Promote Health Equity' (2019) 21 AMA Journal of Ethics 1036 <https://journalofethics.ama-assn.org/article/how-should-crispred-babies-be-monitored-over-their-life-course-promote-health-equity/2019-12> accessed 26 December 2020, where Thompson suggests that such a monitoring plan should include physical, mental as well as social health monitoring on the

raised in the existing debate concerning HGE is often a mere suggestion that long-term follow up should be required to render the clinical use of HGE ethical and responsible;[502] or a mere discussion on the ethical plausibility of long-term follow up programme itself.[503] Thus, I argue that the discussion on how this long-term follow up can be done effectively so as to render a responsible use of HGE in human reproduction and to be in line with children's interests has been overlooked. Although it is laudable that the National Academy of Sciences, when considering the long-term monitoring of the resultant children in its 2020 report, acknowledges that children's voices should be included in procedures (such as HGE) that affect them,[504] there is still a missing piece in this kind of proposal. To render the long-term monitoring system functionable in the first place, it is important that children be equipped with certain information, including that they have been genetically modified prior to birth. I argue that acknowledging and understanding this aspect is particularly helpful in implementing a long-term follow up system more effectively and most importantly, it is in line with a child-centred approach. I suggest that by giving accurate information to children, it may help them understand the importance of the long-term follow up and make informed decisions about whether to continue to enrol in the programme when they reach the age of maturity (more detail in Chapter 6). For now, my proposition is that the current proposal for a long-term follow up, though is argued for the sake of children's health, appears superficial. More clarifications are needed if such a proposal is to better uphold children's interests. In Chapter 6, I explain the need for information in the context of a right to know for children born as a result of HGE through an understanding of the relationship between "capability" and "identity". This understanding can provide a more solid conceptual framework to better explain and support the long-term follow up plan.

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resultant children; also see supra note 56, NAS (2020) where it is provided that 'Comprehensive long-term follow up would include the assessment of: (i) obstetric and perinatal outcomes; (ii) genetic disorders in resulting births; (iii) other health problems in children; (iv) growth, motor, and physical development; (v) cognitive and language development including developmental delay; and (vi) psychological adjustment including mental health problems'.

[502] 'Statement by the Organizing Committee of the Second International Summit on Human Genome Editing' (*The National Academics of Sciences, Engineering and Medicine* November 29, 2018) <http://www8.nationalacademies.org/onpinews/newsitem.aspx?RecordID=11282018b> accessed 26 December 2020; also see supra note 2, NASEM (2017) 123.

[503] Supra note 492, de Wert and Others (2018); See supra note 314, Baylis (2019).

[504] Supra note 56, NAS (2020) 84 (page indicated is from the prepublication copy).

3.2 Conclusion: A Summary of Problems and Gaps in the Existing Debate

From the above discussion, I suggest that the approaches taken, though are child-centric, fail to adequately consider the future children's interests in the context of HGE mainly because:

(a) The *non-identity problem* prompts us to reconsider our obligation towards the future individuals because if we control our action/decision leading to reproduction, the outcome is that we also influence who comes into existence. This, according to the non-identity problem, leaves us in a dilemma in which it is difficult to reasonably justify our claim that certain reproductive choices are wrong or harmful. I stressed that the arguments based on the non-identity problem focus merely on the existence and non-existence of the possible children (thus, focusing only on a type of identity called numerical identity) but it fails to consider the resultant children who may be born via HGE and deserve protection. Therefore, while the non-identity problem flags to us the need to further consider the concept of "identity", there is also a need to find a way around the non-identity problem in order to offer practical contribution to the ethical and regulatory debate relating to HGE with the children's interests properly safeguarded.

(b) The *open future* argument highlights that children should be prepared to be future adults with variety of choices and opportunities available to them when they grow up. I argued that the concept remains ambiguous because of the subjectivity of an "open" and a "closed" future. I also pointed out that having a range of choices available is different from having developed capabilities that lead to more choices. The open future which focuses more on the former thus cannot offer a satisfactory ground in justifying and guiding decision making in relation to the use of HGE. In particular, the open future principle fails to offer a plausible theoretical ground in explaining why and how health-related purpose should be prioritised, in line with a child-centred approach.

(c) The purported *right to an untampered genome before birth* has struggled to find a place within the current regulatory provisions – the common heritage view and the concept of human dignity cannot plausibly establish a protected interest to have non-modified genome for the future individuals. Looking at the international documents such as the 1997 Declaration and the Oviedo Convention, it seems that it is the protection of a “species identity” that was intended. This should not be confused with a right to have a genuine genetic identity (or a right to have unaltered genome).

(d) The current recommendation to have *a long-term follow up* mechanism is indeed needed as a means to properly safeguard the future children’s interests. However, I argued that there is an essential aspect before the proposal can effectively be implemented which has been overlooked – that is, children must be aware of the fact of being genetically modified. Without this knowledge, the proposal is futile in practice.

Building upon these observations, I therefore conclude that there is a need:

(1) *To have a solid philosophical and theoretical foundation to determine, justify and limit the current proposal on the health-related use of HGE.* As indicated, the open future principle fails to achieve this. Having such a framework is important to ensure that “children” and “health” are given sufficient consideration in the process and not merely taken for granted to simply justify the controversial use of HGE.

(2) *To have a detailed analysis on the concept of “identity” since “identity” is a key concept underpinned in the current HGE debate.* As suggested, the non-identity problem focuses on “numerical identity” and the purported right to an untampered genome focuses on “genetic identity”. There is a need to understand different types of identities (including different interpretations of one particular “identity”) and the different weight that each may contribute to the ethical acceptability of HGE. Without this understanding, it would render the overall debate vague and sometimes confusing. Moreover, a thorough examination of “identity” might provide an insight as to why the long-term monitoring proposal is important and how this proposal might be effectively implemented in the context of HGE.

This thesis continues by further exploring these two suggestions.

Chapter 4 – The Capability Approach and its Applications in the Heritable Genome Editing Debate

In Chapter 3, I discussed the unique position of children in the current heritable genome editing ("HGE") debate. Specifically, I explored the non-identity problem, the "open future" argument, the purported right not to have genomes intentionally modified before birth and the current proposal for a long-term monitoring mechanism. Based on this analysis, I argued that "children" have not been adequately safeguarded and could be easily manipulated in the context of HGE, in part because there is a lack of a solid theoretical framework to justify and limit the existing suggestion for a health-related reproductive use of HGE ("the 1st gap").

In this chapter, I discuss some of the ways in which a capability approach brings fundamental insights to the HGE debate, particularly in relation to future children and how these insights help addressing the 1st gap. Having this framework in place is important because it can avoid "children" and "health" being taken for granted in the use of this controversial technology. Hence, my aim in this chapter is to demonstrate that the capability approach has the theoretical and normative resources needed to adequately address future children's interests as well as children's future interests. I argue that in the context of HGE where it is almost always the health of the future children that we are concerned with, the capability approach offers a more valuable tool in the ethical discussion of the possible clinical use of HGE from a child-centred perspective, as compared to other existing arguments put forward in the debate: the non-identity problem and the open future argument (see again Chapter 3). To achieve the aim of this chapter, it is essential for me to first examine some of the main features of the capability approach that are relevant to the context of HGE.

4.1 An Overview of the Capability Approach

In its simplest form, the capability approach emphasises the 'opportunity to achieve certain states or undertake certain activities'.[505] Amartya Sen initially developed the

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[505] See for instance, Amartya Sen, *Inequality Reexamined* (Harvard University Press 1992); Tania Burchardt, 'Capabilities and Disability: The Capabilities Framework and the Social Model of Disability' (2004) 19 Disability & Society 735, 742; Thomas Wells, 'Sen's Capability Approach' (*Internet Encyclopaedia of Philosophy*) <https://iep.utm.edu/sen-

capability approach in the field of economics where it focuses on the actual opportunities that an individual has to do or be what the individual may value doing or being.[506] Since then, the approach has been further developed and applied by Sen himself as well as Martha Nussbaum in contemporary political philosophy, particularly dealing with the issues of justice.[507] In what follows, I highlight three main features of Sen's and Nussbaum's capability approach to provide the basis for the development of my arguments in the next section.

First, "capability" is distinguished from "functionings" in the capability approach, though both are closely related.[508] Here, functionings are the actual, achieved states or activities by an individual, for example being educated and being nourished. Capabilities are the different types of functioning that one *can* achieve. In other words, capabilities are the combination of both actual and potential functionings, and it reflects the individual's real freedom in deciding and leading the kind of life he/she values.[509] The capability approach stresses the expansion of capabilities so as to highlight the genuine freedom of one making choices that matter to him/herself.[510] It is worth noting that, as Robeyns reminds us, not all functionings one values are automatically taken as constitutive of well-being and deserve protection. For instance, following Nussbaum's example, she observes that the capability to rape is not something that society is bound to protect.[511] Hence, not all the claims for an expansion of capabilities are ethically acceptable; there is a need to also consider and justify the functionings to be achieved through the capabilities.

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cap/#:~:text=The%20Capability%20Approach%20is%20defined,they%20have%20reason%20to%20value.&text=Within%20academic%20philosophy%20the%20novel,attracted%20a%20number%20of%20scholars> accessed 26 December 2020.

[506] Amartya Sen, 'Development as Capability Expansion' (1989) 19 Journal of Development Planning 41; Amartya Sen, 'Well-Being, Agency and Freedom' (1984) 82 Journal of Philosophy 169; ibid, Sen (1992).

[507] See for instance, Amartya Sen, 'What do we want from a Theory of Justice?' (2006) 3 Journal of Philosophy 215; Martha Nussbaum, *Frontiers of Justice: Disability, Nationality, Species Membership* (The Belknap Press 2006); Martha Nussbaum, 'Human Functioning and Social Justice: In Defense of Aristotelian Essentialism' (1992) 20 Political Theory 202.

[508] See for instance, supra note 506, Sen (1989) 43-44.

[509] For instance, see Martha Nussbaum and Amartya Sen, 'Introduction' in Martha Nussbaum and Amartya Sen (eds), *Quality of Life* (Oxford Scholarship Online 2003) 3.

[510] Supra note 506, Sen (1989).

[511] Ingrid Robeyns, 'Capabilitarianism' (2016) 17 Journal of Human Development and Capabilities 397, 406.

The second feature of the capability approach is that there are different "conversion functions" in which different individuals would have different abilities to convert certain given resources (such as legal entitlements) into functionings.[512] Sen claims that the notion of capability deals with the opportunity aspect of freedom, highlighting that although two persons can have the same set of entitlements, they may not have the same set of opportunities to exercise the entitlements (thus, they differ in their capabilities to utilise the entitlements).[513] For instance, freedom of speech is a common human right,[514] but not everyone can exercise it freely – one may not exercise it due to a lack of knowledge of having such human rights or because of the political structure in place which heavily constrains such entitlement. Hence, the capability approach acknowledges not only the "inputs and outcomes" but also the "process" that influences the implementation of the entitlements (or in other words, the functionings).[515] Following this understanding, the capability approach not only deals with an individual's personal condition, but it also considers that individual's condition within the bigger context, including the cultural, religious, societal and political factors (the individual, social, and/or environmental factors are also known as the "conversion factors").[516] This is thus different from a rights-based approach in which the focus is on the fulfilment of some formal rights that people should enjoy. Unlike a capability approach, a rights-based approach does not consider the conversion factors and therefore pay no attention to whether or not the right can actually be exercised.[517]

Third, within the capability approach, certain types of capabilities are deemed more essential than others, hence, capabilities are not 'of equal moral worth'.[518] Although

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[512] Ibid, 407.

[513] See for instance, Amartya Sen, 'Human Rights and Capabilities' (2005) 6 Journal of Human Development 151, 154. Note, however, Sen argues that the notion of capability may not be able to adequately deal with another aspect of freedom, that is the process aspect of freedom. This is because, as Sen argues, such a notion is not sufficient to deal with the fairness of procedure (see 155-156).

[514] The Universal Declaration of Human Right 1948, Article 19.

[515] Rodrigo López Barreda, Joelle Robertson-Preidler and Paula Bedregal García, 'Health Assessment and the Capability Approach' (2019) 30 Global Bioethics 19, 24.

[516] Ingrid Robeyns, 'The Capability Approach: A Theoretical Survey' (2005) 6 Journal of Human Development 93, 99.

[517] See supra note 506, Sen (1989); also see supra note 505, Wells (accessed 26 December 2020).

[518] Christopher Riddle, 'Well-Being and the Capability of Health' (2013) 32 Topoi 153, 159.

Sen refuses to list the most basic capabilities as he claims that this is to be done democratically in the public policy process,[519] some insights on what might be on the list are, implicitly, discernible from his work.[520] For instance, he explains the notion of 'basic capabilities' to include the abilities to do certain basic things such as the ability to be nourished or live a life 'disease-free'.[521] Nussbaum, on the other hand, explicitly supplies a list of ten central human capabilities which include 'life'; 'bodily health', 'bodily integrity'; 'senses'; 'imagination and thought'; 'emotions'; and 'practical reason',[522] although she argues that the list is not exhaustive as in it is open-ended and is subject to frequent revision by the society.[523] Nussbaum claims that basic capabilities involve inborn capacities of individuals that are necessary for expanding the more advanced capabilities.[524] Drawing from this background, in the rest of this chapter, I shall discuss how "health" is seen as one essential capability. I argue that "health capabilities" ought to be deemed one of the basic, thus central capabilities and that this understanding has significant relevance to the context of HGE. In the later chapter where I explain different types of "identity", I will further argue that there is one type of "identity" which can and should also be deemed one of the central capabilities, but for now, the focus of this chapter will only be on "health".

4.2 Relevance of the Capability Approach to the Context of Human Heritable Genome Editing

In this section, I discuss how incorporating a capability approach into the context of HGE can bring fundamental insights to the debate. In particular, I first argue that a

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[519] Amartya Sen, 'Capabilities, Lists, and Public Reason: Continuing the Conversation' (2004) 10 Feminist Economics 77; see also Amartya Sen, 'Human Rights and Capabilities' (2005) 6 Journal of Human Development 151, 157.

[520] Krushil Patricia Mairingi Watene, *Strengthening the Capability Approach: The Foundations of the Capability Approach, with Insights from Two Challenges* (PhD Thesis, University of St Andrews 2010) 25.

[521] See for instance, Amartya Sen, 'Capability and Well-being' in Martha Nussbaum and Amartya Sen (eds) *The Quality of Life* (Oxford: Clarendon Press 1993).

[522] Martha Nussbaum, *Creating Capabilities: The Human Development Approach* (Harvard University Press 2011) 33-34.

[523] See supra note 507, Nussbaum (2006) 78.

[524] Martha Nussbaum, *Sex and Social Justice* (Oxford University Press 1999) 44. Nussbaum distinguishes between basic, internal and combined capabilities: internal capabilities are the developed states of the person that are sufficient conditions for the exercise of the requisite functions; combined capabilities connote both internal capabilities and external factors in order for future freedoms and opportunities to be secured.

capability approach provides the conceptual framework to understand the significance of preserving capabilities for children especially in relation to their innate capabilities (basic capabilities). Also, as the capability-based framework is outcome-oriented, it captures future children well and avoids the conceptual difficulties often fraught within a rights-based framework when future (unborn) children are involved. Once I establish the importance of children being able to develop core capabilities, I then move on to argue how health capabilities are among those capabilities that deserve more ethical attention and how this understanding can fill the current theoretical gap in the existing recommendation for a health-related use of HGE. Lastly, I further argue that the notion of central health capabilities can provide an evaluative space to determine which kind of genetic conditions ought to be given priority in the regulations of HGE.

4.2.1 Preserving capabilities for children

I argue that the incorporation of a capability approach in the HGE debate provides a better and more practical defence of future children's interests than one of the dominant approaches in the existing discussion, such as the open future principle. Setting aside the subjectivity on the interpretations of the "open" future, the gist of the claim for an open future is that there should be an obligation not to act in such a way that would curtail the future opportunities available to children when they grow into adults; or more controversially, there should be an obligation to act in such a way that promotes the future abilities of children so that they can exercise their rights in the future from the available options (see Chapter 3, section 3.1.2). Essentially, as discussed in Chapter 3, the open future principle, by emphasising children having a range of options or opportunities to choose from when they grow up, seems to be focusing on the future autonomy that children should have, thus seeing children as "becomings" – the future beings that they will become. This is different from the view that emphasises having developed capabilities to utilise certain (even limited) options and further lead to a range of other choices. Unlike the open future principle, the capability approach captures the latter, which sees children not only as "becomings" but also as "beings" that have an interest to develop core capabilities.[525] In what follows, I first point out two distinct yet related aspects of the capability approach in the context of children to demonstrate how a capability approach perspective can capture the importance of children's interests in relation to their capabilities.

The first aspect I would like to highlight here is that "capacity" can be distinguished from "capability" although these words have sometimes been used interchangeably in the literature. As discussed earlier, "capability" in the capability approach means the genuine opportunity that one has in order to achieve what he/she truly values, and these include both actual and potential functionings. "Capacity", on the other hand, can be understood as "attributes" or "abilities" of the individual.[526] An example following this understanding would be that the *capacity* to make a medical decision is different from the *capability* to make such a decision. In the adult context, one is deemed to have the *capacity* to decide on medical treatment if he/she is sound-minded.[527] Meanwhile, when addressing the *capability* to make a medical decision from a capability approach perspective, the concern is whether there are real opportunities that he/she can utilise his/her capacities (in this instance, the capacity to decide on certain medical treatment).[528] The factors to be considered here could be the political structure in place for example, whether there is a legal framework that is protecting or promoting autonomous choices in medical decision making. This understanding of "capacity" and "capability" can also be applied to children, albeit in a slightly different way. It is often emphasised that children are not a unified group, in the sense that an infant is not the same as a child at the age of 6 or a young person at the age of 14 or 15 in terms of their capacity

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[525] Noam Peleg, 'Reconceptualising the Child's Right to Development: Children and the Capability Approach' (2013) 21 International Journal of Children's Rights 523.

[526] Ibid, 73.

[527] Mental Capacity Act (2005); see also National Health Service (NHS), 'Assessing Capacity: Consent to Treatment' (2019) <https://www.nhs.uk/conditions/consent-to-treatment/capacity/> accessed 26 December 2020.

[528] Or, in the context of the patient who lacks mental capacity, whether he/she would be able to do so (e.g. to reach a particular medical decision with his/her best interests in mind) with the supports of others. The Mental Capacity Act 2005 (for England and Wales) can be seen as a legal structural support that promotes the capabilities of people lacking mental capacity to make their own decisions relating to their care and treatment.

and capability.[529] When children age or grow up, their ‘cognitive, physical, social, emotional and moral capacities’ (usually) develop accordingly, which impacts the way they communicate, make or evaluate certain decisions or judgments and take actions.[530] Therefore, the concept of *evolving* capacity is more suitable when we are considering children. The concept of evolving capacities of children is well-explained by Lansdown. In light of the United Nations Convention on the Rights of the Child (“UNCRC”), he notes that such a concept strikes a balance between protecting the children due to their ‘immaturity and youth’ while at the same time also recognising children as active agents with increasing autonomy in the exercise of rights given to them in the UNCRC.[531]

Although the concept of evolving capacities can explain that children are developing and may have limited autonomy depending on their age, maturity and experience but are still in need of protection, it fails to capture the conditions and grounds for the development and use of their capacities. This is where the capability approach stands out as it captures the notion that capacities also depend on certain ‘living conditions beyond the subject’s reach or which exist independently of the individual subject’.[532] As Sen notes, ‘what opportunities children have today and will have tomorrow, in line with what they can be reasonably expected to want, is a matter of public policy and social programmes, involving a great many agencies.’[533] In the context of children, the concept of *evolving capability* is more relevant because not only do children have dynamic capacities, but they also have expanding capabilities (their capabilities are developing gradually following their evolving capacities and other societal/environmental factors).[534] It is worth noting that the evolving

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[529] Jerome Ballet, Mario Biggeri and Flavio Comim, ‘Children’s Agency and the Capability Approach: A Conceptual Framework’ in Mario Biggeri, Jerome Ballet and Flavio Comim (eds), *Children and the Capability Approach* (Palgrave Macmillan 2011) 33, 34.

[530] Gerison Lansdown, *The Evolving Capacities of the Child* (Innocenti Insight, UNICEF 2005) xiii.

[531] Ibid, ix.

[532] Manfred Liebel, ‘From Evolving Capacities to Evolving Capabilities: Contextualizing Children’s Rights’ in Daniel Stoecklin and Jean-Michel Bonvin (eds), *Children’s Rights and the Capability Approach: Challenges and Prospects* (Springer 2014) 73.

[533] Amartya Sen, ‘Children and Human Rights’ (2007) 1 Indian Journal of Human Development 235, 243. Note that Sen is viewing children as ‘becomings’ as he doubts if children can exercise agency, that is to make choices according to the values they have.

[534] Supra note 529, Ballet, Biggeri and Comim (2011) 33, 34.

capability concept need not be entirely divided from the concept of evolving capacity. Instead, the former can be said to have included the latter. This is in line with Nussbaum's understanding of capabilities, in which she includes basic, internal, and combined capabilities. According to Nussbaum, the internal capabilities resemble capacities in that they include the features of an individual such as his/her personalities, cognitive capacities, and states of physical health.[535] This clearly suggests that capability as a whole includes capacities of the individual. Improving the capabilities of children may then enhance the capacity of children.[536] Consequently, there should be more attention given to facilitating the capabilities of children.

The second aspect I would like to pinpoint is that the capability approach explains that children's capabilities are interconnected. The interdependent nature of children's capabilities suggests that having one capability (or more) may impact one's other capabilities. For example, on children's right (or capability to seek the right) to asylum, the guarantee of this right and/or capability of the right further promotes other more general capabilities such as the capability to be in good health; to be well-nourished; to life and survival. In other words, the latter capabilities can only be achieved if the children are first given access to asylum. Similarly, it is also true that only if the child has the latter capabilities such as the capability to life, survival or health, then he/she can actually exercise the capability to seek asylum.[537] Also, as with Hollingsworth's argument for a category of rights called 'foundational rights' (in the context of youth justice) to be given special protection in order to ensure full autonomous rights upon reaching adulthood,[538] getting the basic capabilities especially during childhood guarantees the capabilities that they may have when they become an adult. It is suggested that in terms of children's capabilities, the instrumental role of capabilities and functionings is more substantial than it is for adults because 'the absence of a key functioning or capability not only

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[535] Supra note 522, Nussbaum (2011) 21.

[536] Mario Biggeri and Ravi Karkara, 'Transforming Children's Rights into Real Freedom: A Dialogue Between Children's Rights and the Capability Approach from a Life Cycle Perspective' in Daniel Stoecklin and Jean-Michel Bonvin (eds), *Children's Rights and the Capability Approach: Challenges and Prospects* (Springer 2014) 25.

[537] Jonathan Josefsson, 'Children's Rights to Asylum and the Capability Approach' (2016) 23 Ethical Perspectives 101.

[538] Kathryn Hollingsworth, 'Theorising Children's Rights in Youth Justice: The Significance of Autonomy and Foundational Rights' (2013) 76 Modern Law Review 1046, 1049.

constrains other capabilities, but also limits the capacity to develop new capabilities over time'.[539]

Applying these two aspects of children's capabilities in light of the possible clinical use of HGE, one can argue that the technology ought to only be used to secure and facilitate the *basic* capabilities so that the children can be born equipped with the necessary capabilities to further other capabilities (including the internal capabilities) during their childhood as well as when they grow up. I will further explain what I think these "basic capabilities" can (and should be) in the context of HGE in my point (2). Before that, it is important to stress that the capability approach applies to *future* children as well. As suggested by Watene, since the capability approach is 'outcome-oriented' in that it considers whether there are genuine opportunities in place for one to exercise certain entitlements, future people are arguably included in the approach.[540]

It is now time to revisit the "well-being threshold principle" first suggested in Chapter 3 when I discussed the non-identity problem. I argue that the capability approach provides constructive inputs to the development of a well-being threshold principle that captures and reflects the basic threshold of human well-being in the context of future children. Adopting a well-being threshold principle will involve an *absolute* understanding of harm in which it is relevant and valid for all individuals notwithstanding their (numerical) identity.[541] The relevant question will be whether the well-being of the future child is at or above the acceptable threshold. As Gutwald and others explain, 'if a person is in a sub-threshold-state, we can say that she is ipso facto harmed, even if she was brought into existence by the action related to that state'.[542] Hence, this principle avoids the issue of having to compare the state of one who exists with the state that he/she does not exist as faced by the non-

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[539] Mario Biggeri, 'Capability Approach to Children's Well-Being and Well-Becoming' in Enrica Chiappero-Martinetti, Siddiqur Osmani and Mozaffar Qizilbash (eds), *Cambridge Handbook of the Capability Approach* (Cambridge University Press 2021).

[540] Supra note 520, Watene (2010) Chapter 6, 108.

[541] Rebecca Gutwald, Ortrud LeBmann, Torsten Masson and Felix Rauschmayer, 'A Capability Approach to Intergenerational Justice? Examining the Potential of Amartya Sen's Ethics with Regard to Intergenerational Issues' (2014) 15 Journal of Human Development and Capabilities 355, 363.

[542] Ibid.

identity problem.[543] In defining what this threshold should be in the context of HGE, it is important to be reminded that as I pointed out earlier, within the capability approach, there are capabilities that are deemed more essential than the others. This is in line with Nussbaum's observation in her list of the ten central human capabilities which are deemed more important than others. Nussbaum points out that 'if people are below the threshold on any one of the capabilities, that is a failure of basic justice, no matter how high up they are on all the others'.[544] My point here is not to elaborate on Nussbaum's list of central human capabilities with the notion of justice but simply that basic capabilities are central capabilities that should be given more attention as compared to other capabilities. I argue that in the context of HGE, an acceptable well-being threshold can be constructed based on the capability approach, particularly through further understanding and defining the basic capabilities.

It is not a far-fetched idea, particularly in the context of assisted reproductive technologies, to argue for children to be born at least with a threshold level of capabilities and that children will be harmed if their well-being falls below a certain standard, even if there was no alternative option available for them to be born. Although defining the threshold is widely debatable,[545] this line of thoughts – that children should be born with at least certain well-being threshold – has received much discussion in the literature. For instance, Steinbock claims (as pointed out in Chapter 3) that there should be a 'minimally decent existence' ensured at birth as the prospective children's basic interests.[546] Steinbock argues that a minimally decent existence is where the life 'holds a reasonable promise of containing the things that make human lives good: *an ability* to experience pleasure, to learn, to have relationships with others (my emphasis)'.[547] While I cannot fully explore Steinbock's standard for what should amount to a "decent existence" in this thesis,

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[543] Ibid.

[544] Supra note 507, Nussbaum (2006) 167.

[545] See Guido Pennings, 'Measuring the Welfare of the Child: In Search of the Appropriate Evaluation Principle' (1999) 14 Human Reproduction 1146.

[546] Supra note 355, Steinbock (1986) 19. See also, Bonnie Steinbock, 'Wrongful Life and Procreative Decisions' in Melinda Roberts and David Wasserman (eds), *Harming Future Persons* (Springer, Dordrecht 2009) 163.

[547] Ibid.

I must emphasise that it is the aspect of such a standard by Steinbock that is the focus here, i.e. *the capabilities* of the children to live a "good" life. Also, David Archard argues for a so-called birth right where he claims that it is a right that any prospective child has 'not to be intentionally and knowingly conceived with the reasonable prospect of not enjoying a life above a certain threshold'.[548] Archard's idea is that children should be born *capable* of enjoying certain rights (e.g. those rights enshrined in the UNCRC) to lead an adequate life. Daniels also stresses the *abilities* that are needed for one to enjoy a normal range of opportunity in a society.[549] Pennings also suggests that 'an individual has a decent welfare level when he has the *abilities and opportunities* to realise those dimensions and goals that in general make human lives valuable (my emphasis)'.[550] All of this echo what has been the core for the capability approach – the opportunities in terms of capabilities one should have in order to achieve real freedom. Magnusson observes that while we can reasonably disagree of what kind of rights the child will eventually fulfil, 'it is reasonable to think they include (at the very least) rights to the satisfaction of the basic interests require to lead minimally decent lives'.[551] The capability approach can provide some fundamental normative standards such as, defining a threshold that leads to 'freedom of leading a life held to be valuable'.[552] This can be done by maintaining a feasible metric on the 'objective capabilities of people that should be preserved' which includes basic human needs deemed valuable now and will be considered valuable in the future.[553]

While these abilities and opportunities can indicate both external and internal factors, for this part of the thesis, I focus on the internal ones, particularly the innate capabilities that constitute the basic capabilities. The application of the capability approach to the well-being threshold principle then constitutes the claim that a child

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[548] David Archard, 'Wrongful Life' (2004) 79 Philosophy 403, 405.

[549] Norman Daniels, *Just Health Care* (Cambridge University Press 1985).

[550] Supra note 545, Pennings (1999) 1148.

[551] Erik Magnusson, 'Children's Rights and the Non-Identity Problem' (2019) 49 Canadian Journal of Philosophy 580, 587.

[552] Ibid, 363-364.

[553] Ibid.

is harmed at birth when his/her well-being falls below the threshold by the basic capabilities. This claim is useful in acting as a valid ground when contemplating the possible circumstances in which we allow clinical application of HGE. In particular, I argue that in the circumstances where we can control what kind of children we "create" with the help of technology such as HGE, more attention should be given to the resulting children who are the actual subjects of the technology. Given the distinctive feature of HGE (see again Chapter 1), the technology ought to be restricted to the cases where children who will otherwise be considered harmed for not being born preserved with the basic capabilities that are necessary for them to further develop other capabilities. Where in a situation in which a child is not foreseeably harmed at birth (that is when it can be reasonably presumed that the child will be born preserved with basic capabilities without having to use HGE), HGE is then not ethically acceptable, for the child might instead be harmed by resorting to HGE which has a risk of causing significant harm associated with the edits of genes/genomes before birth, e.g. the undesirable side effects that may only reveal during the lifetime of the resultant child. The above views are in line with the reasoning that 'a harmful act may be justified if it prevents/avoids a greater harm. It cannot be justified by virtue of the pure benefits it causes'.[554] In this sense, HGE is deemed a harmful act[555] and it can only be justified when it is used to prevent a greater harm (i.e., when the child will be born below the threshold of basic capabilities). Its use cannot be justified merely because it brings someone into existence (causing someone to exist is deemed a pure benefit in Jacobs' writing).[556] In the next two sections, I further clarify that one of the basic capabilities that should be given special moral importance in the context of HGE is the health capabilities.

4.2.2 The importance of health within the capability approach

As indicated, HGE may, in the future, only be permitted for compelling reasons for "treating" or preventing serious diseases.[557] In September 2020, the National

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[554] Supra note 327, Jacobs (2015), 697.

[555] Ibid. Jacobs exemplifies "surgery" as a harmful act but will be justified in certain circumstances. Thus, one can contemplate a harmful act as being an invasive act. The use of HGE has also occasionally be described as 'gene surgery' (see e.g. supra note 4, Greely (2019)) which directly influences the development of embryos.

[556] Ibid, 697.

[557] For a detailed discussion, see supra note 2, NASEM (2017) 113-115.

Academy of Sciences (NAS) recommended, inter alia, that the initial use of HGE should be limited to serious monogenic diseases.[558] While NAS's recommendation for limiting the current use of HGE to only 'serious monogenic diseases' appears strict and reasonable considering the distinctive feature of HGE, there is still a lack of nuanced explanation of why health-related purpose deserves prioritisation in the clinical use of HGE. I argue that having a philosophical grounding for the purported use of HGE is constructive, especially if we are serious about protecting children's interests. This is because it avoids "health" being used as a gateway to go ahead with controversial genetic technology like HGE. In this section, I show that the capability approach can provide the basis for why "health" (or more accurately, "health capabilities") should be given special ethical consideration.

While Sen's and Nussbaum's work offer meaningful insights on capabilities and human rights, Jennifer Ruger's account of the capability approach provides a notion of capability directly applicable to "health" which, as I shall argue, can serve as a normative framework in the overall evaluation of the possible clinical applications of HGE. Whereas Ruger introduced what she called a 'health capability paradigm' in light of health policy, it is important to make clear here that by adopting Ruger's approach, this thesis *does not* intend to introduce HGE as part of health policy which otherwise would raise controversial eugenic concerns (see Chapter 2). Rather, my thesis is to utilise Ruger's approach in assessing the ethical applicability of HGE in the clinical setting. In this section, I first establish the special moral importance of health within the capability approach which can help to justify why a health-related purpose of HGE is more ethically acceptable compared to enhancement purpose (as defined in Chapter 1).

Ruger proposes a capability view of health where health capabilities, instead of health care or health, are given significant moral weight because 'of its status as an end of political and societal activity'.[559] In this sense, Ruger's focus is on the genuine opportunities one has to achieve the health goals.[560] Health capabilities thus

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[558] Supra note 56, NAS (2020).

[559] Jennifer Prah Ruger, 'Health, Capability, and Justice: Toward a New Paradigm of Health Ethics, Policy and Law' (2006) 15 Cornell Journal of Law and Public Policy 403, 436.

[560] Supra note 515, Barreda and Others (2019) 22.

constitute both the ability and freedom of individuals to achieve certain health functioning.[561] Ruger agrees with Sen in noting that capabilities and functionings are correlated. She highlights that health capabilities can be evaluated by what an individual actually has (the actualised functioning) together with his/her alternative options available to him/her (the possible alternative functioning). For instance, two individuals with diabetes living in different environments (one living in an industrialised society where free insulin is available, while the other is living in a country where there is limited health care service thus no free insulin available) may affect their health capabilities and consequently, overall health functionings.[562] In this sense, capability can be understood as a 'substantive freedom to achieve alternative functioning combinations'.[563] From the examples given, the one with free insulin service may be able to keep up with consistent medication and maintain overall health. In contrast, the other may suffer a further deterioration in the condition and risk getting other symptoms if not able to keep up with consistent medication. The individual in the latter category then arguably has lower health capabilities. Ruger argues that improving one's health capabilities involves preventing, treating, and compensating for constraints that affect their capabilities for health functioning.[564] Following this, the one with free insulin service is said to have been compensated for the constraints that may be caused by diabetes. The above example illustrates how health capabilities can be evaluated against relative circumstances. Yet, it is equally important to note that they can also be affected by personal factors in respect of one's body functions and structures.[565]

The reason why health capabilities are of moral significance can be explained through the concepts of fertile functioning and corrosive disadvantage. Nussbaum

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[561] Jennifer Prah Ruger, *Health and Social Justice* (Oxford University Press 2010) 81.

[562] Iain Law and Heather Widdows, 'Conceptualising Health: Insights from the Capability Approach' (2008) 16 Health Care Analysis 303, 312.

[563] Jennifer Prah Ruger, 'Toward a Theory of a Right to Health: Capability and Incompletely Theorized Agreements' (2006) 18 Yale Journal of Law & the Humanities 273, 295.

[564] Supra note 561, Ruger (2010) 83.

[565] Sophie Mitra, 'The Capability Approach and Disability' (2006) 16 Journal of Disability Policy Studies 236, 239.

suggests that the concept of 'fertile functioning' and 'corrosive disadvantage'[566] may help determine which capabilities should be given priority.[567] Fertile functioning is able to "promote" other relevant capabilities. On the other hand, corrosive disadvantage can be understood as a deprivation that brings huge impacts on the other areas of one's life.[568] Following this, being educated can be one example of fertile functioning while a lack of education may be seen as corrosive disadvantage (for instance, when the lack of education leads to continuing poverty).[569] This can similarly be applied in the health context. I argue that health capabilities can be both fertile functioning/capabilities[570] and corrosive disadvantage. This is because, as Ruger points out, health capabilities, especially the central ones (to be discussed in point 3 below), facilitate many other capabilities. At the same time, without having the central health capabilities, it would mean that one is deprived of many other capabilities (many opportunities that the individual could have achieved). In a similar vein, many other commentators have argued for the role of health from a capability perspective. For instance, Riddle argues that 'health plays a special role in the promotion of well-being within the capabilities approach framework'[571] on the basis of the types of disadvantages connected with a failure to secure good health.[572] He explains that 'one may very well suffer disadvantage from failing to secure a valuable thing, but that disadvantage is only corrosive when it reaches into other aspects of that individual's life, and negatively impacts the ability to secure other valuable states of being'.[573] Kinghorn also suggests that 'health is a capability of central importance' and that 'we value a broader set of capabilities *only if we are experiencing some level of health* which is not catastrophically restrictive and

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[566] Note that these ideas are originated from Wolff and De-Shalit, see Jonathan Wolff and Avner De-Shalit, *Disadvantage* (Oxford Scholarship 2007).

[567] Supra note 522, Nussbaum (2011) 44-45.

[568] Ibid, 44.

[569] Supra note 566, Wolff and De-Shalit (2007).

[570] Supra note 522, Nussbaum (2011) 44. Nussbaum views that Wolff and De-Shalit do not clearly distinguish "functioning" and "capability".

[571] Supra note 518, Riddle (2013) 153.

[572] Ibid, 156-157.

[573] Ibid, 157.

distressing (emphasis added)'.[574] Therefore, in the context of capabilities, it is arguable that health is in a special category of capabilities that are imperative conditions for other capabilities. Following this, there seems to be a case to argue for prioritising a health-related use of HGE based on a health capability approach since health capabilities are "fertile" and ensuring these may remove the "corrosive disadvantage".

By adopting the position that capabilities are not of equal moral worth and that some capabilities are more important to human well-being even among a list of central capabilities, one can deal with a possible critique which may arise from my argument here: the opponents may raise that if the expansion of capabilities can promote the well-being of the future children, then, in principle, not only health-related application can justify the clinical use of HGE, but also those related to enhancement purpose. This sentiment can be traced back to the therapy-enhancement distinction debate first flagged in Chapter 1. For instance, there has been argument that there is no moral significance in distinguishing the concepts as there is no difference between therapeutic and enhancement use from the perspective of well-being. This view focuses on the eventual consequences that an action (e.g. the use of genetic technologies) will bring about. Just as what John Harris and Julian Savulescu claim (controversially), if the concern is for our future children's well-being, not only that the parent should aim to prevent them from pain and suffering caused by diseases, but the parents should also enhance their children.[575] This is because, it is argued, both therapy and enhancement can improve the child's well-being by providing more ranges of opportunities for the children. Nonetheless, following the health capability approach which emphasises the moral significance of health capabilities, one can explain why the health-related purpose of HGE can be ethically allowed in the clinical setting but not for other enhancement purposes (such as to improve children's intelligence level, assuming for now that this can be achieved through genome editing in the future) even when both might contribute to the overall well-

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[574] Philip Kinghorn, 'Exploring Different Interpretations of the Capability Approach in a Health Care Context: Where Next?' (2015) 16 Journal of Human Development and Capabilities 600, 614.

[575] Supra note 179, Harris (2007); Julian Savulescu and Nick Bostrom, *Human Enhancement* (Oxford University Press 2009). Authors make the highly controversial claim that pursing genetic enhancement is not only morally permissible but also morally desirable (that parents are morally obligated to pursue genetic enhancement). This view is highly debated and is often viewed as 'new eugenics'. See for instance, Robert Sparrow, 'A Not-So-New Eugenics: Harris and Savulescu on Human Enhancement' (2011) 41 Hastings Center Report 32.

being of children. This is in line with the previous argument that HGE should be adopted only in a way that the resulting children would be *capable* of enjoying the entitlements available for them, more particularly, children should be born equipped with a certain well-being threshold by basic capabilities. Whilst "health" is seen as an important capability by many other scholars, Ruger's health capability paradigm has another feature that helps facilitating a core concept of "health" much needed for the HGE debate. I shall turn to this in the next point.

4.2.3 Defining "health" using the capability approach: Prioritisation of central health capabilities

Merely regarding health as a basic capability with moral significance is not enough to appropriately safeguard future children's interests in the HGE-related policy because "health" may still be easily manipulated in a way to conceal the risks of this contentious procedure. A clearer account of "health" is therefore needed, especially considering that more and more genetic-related diseases or disorders can be identified with the rapid advancement of genetic knowledge and technologies. The increasing list of diseases/disorders is implied by the NAS in its 2020 report: despite it recommends for the initial use of HGE to be confined to only serious single-gene disorders; it at the same time also suggests that the 'clinical use of HGE should proceed incrementally'.[576] Sooner than we know, there may be a time where the list of single-gene disorders will be expanded greatly and/or that polygenic disorders will be identified with much scientific certainty.[577] When that is the case, there must be a normative framework already in place for the stakeholders, including the policymakers to evaluate whether a certain proposed use of HGE is (or can be) ethically permissible.

I argue that Ruger's health capability paradigm which further distinguishes central and non-central health capabilities in health policies will be helpful in the regulations of HGE in that it explains which kind of use of the technology may be ethically permissible (or should be prioritised). This being said, I suggest that additional reframing of the content of central health capabilities is needed for the

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[576] Supra note 56, NAS (2020).

[577] Supra note 409, Gyngell, Douglas and Savulescu (2017) 500-503.

context of HGE. While health capabilities are of moral significance, Ruger argues that it is the *central* health capabilities that should be prioritised in health policies.[578] While Ruger does not discuss in detail what would amount to non-central health capabilities, from her text it can be assumed that non-central health capabilities are those in which disagreement might arise within and across societies. Ruger argues that 'the selection and valuation of non-central health capabilities should be left open to be selected and weighted through public discussion and public process of a joint scientific and deliberative approach'.[579] One can stipulate Ruger's central health capabilities using an objective definition of health while leaving the subjective definition of health for an account of non-central health capabilities in which a degree of social and cultural meanings may be involved. I would like to focus on the notion of central health capabilities for the purpose of this thesis.

Ruger acknowledges that it may be difficult to resolve different accounts of health based on epistemological variations, yet she thinks that it is possible to reach an agreement for a 'global view on health's core dimensions'.[580] Ruger defines central health capabilities as 'the capability to avoid premature mortality and the capability to avoid escapable morbidity'[581] (she further explains escapable morbidity to include 'disease, dysfunction, deformity, malnutrition, disability')[582] and in one occasion, she also indicates that the central health capabilities 'are necessary conditions for humanity, regardless of social context' and they include 'the capacity of our organs and systems to function'.[583] First setting aside the contents or criteria of Ruger's central health capabilities, the point I wish to establish in this instance is that there are certain elements of health capabilities that can be deemed universal to many (if not all) of us despite the societal setting. Following Ruger, there should be general

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[578] Supra note 561, Ruger (2010) 94.

[579] Supra note 561, Ruger (2010) 113. In developing her framework, Ruger incorporates a social choice model known as the 'incompletely theorised agreements' – a framework for resolving conflicts among divergent views. Supra note 559, Ruger (2006) 311. The gist of the incomplete theorisation is that it takes into consideration the pluralism within societies and people can come to an agreement on certain decisions without having to agree on the philosophical or metaphysical issues (as Ruger exemplifies with the questions such as 'what is human flourishing?').

[580] Supra note 561, Ruger (2010) 79.

[581] Supra note 561, Ruger (2010) 98; also supra note 559, Ruger (2006) 302.

[582] Supra note 561, Ruger (2010) 113.

[583] Supra note 561, Ruger (2010) 76.

attention to these central health capabilities and that addressing/improving these capabilities should be the moral concern and the primary purpose of health policy and law.[584] In regulating how HGE ought to be implemented in the reproductive settings, I argue that only those *central* health capabilities should be ethically allowed given the controversial features of HGE. However, there is a need for clarification on Ruger's central health capabilities for it to be feasible in the context of HGE.

I suggest reframing Ruger's criteria for central health capabilities to better fit in the context of HGE. This is because her original criteria were made in the general context of health policies (e.g. dealing with the issue of resource allocation) and when applied strictly to the regulations of HGE, it would likely be too broad in the sense that a wide range of genetic diseases or disorders could easily be deemed affecting the central health capabilities and thus fall under the permissible application. Especially with her explanation of the 'capability to avoid escapable morbidity' where she includes disability and dysfunction in the definition, applying these criteria to the context of HGE without careful consideration would invite, as one can imagine, concerns from eugenic perspective as well as disabilities studies. Furthermore, what amounts to "premature mortality" is also not clearly defined. In one of its report in 1998 which offers a vision of future up to the year of 2025, the World Health Organisation indicates that premature death is death that happens before the age of 50.[585] This definition is however deemed arbitrary; in fact, the concept of premature death has been criticised as ambiguous to be a basis for evaluation of harm.[586] Additionally, a low threshold for central health capabilities (in that it would easily cover a broad range of diseases/disabilities) is not feasible in the regulations of HGE considering its distinctive features and the disruptive effects that HGE may bring to human life.[587]

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[584] Supra note 559, Ruger (2006) 302.

[585] World Health Organization, *The World Health Report 1998 - Life in the 21st Century: A Vision for All* (World Health Organization 1998) <https://www.who.int/whr/1998/en/whr98_en.pdf> accessed 01 September 2021.

[586] Brooke Alan Trisel, 'What is Premature Death?' (2007) 11 An Internal Journal of Philosophy <http://www.minerva.mic.ul.ie/vol11/Premature.html> accessed 8 August 2021.

[587] Paul Martin and Others, 'Genome Editing: The Dynamics of Continuity, Convergence, and Change in the Engineering of Life' (2020) 39 New Genetics and Society 219.

Thus, I propose to define central health capabilities for the purpose of this thesis as the capabilities to avoid early-onset diseases that cause severe cognitive or mental impairment. Having the basic cognitive function should be categorised as a central health capability that will facilitate many other capabilities. Mameli's explanation on the requirements in order to be able to choose one's life plan is useful here for us to reflect on what a basic cognitive skill might entail:

> 'People must have cognitive and emotional skills that make them able to (a) compare (consciously or unconsciously) different life plans, (b) select one among those life plans they are able to consider, (c) transform this choice into the intention to behave in accordance with the chosen plan and (d) transform this intention into behaviour that actually conforms to the chosen option'.[588]

Although this paragraph of Mameli was made in the context of open future, taking a capability approach perspective can explain the gist of the paragraph. In order for the children to exercise "autonomy" or future autonomy such as to make different life plans, to process choices and to implement them, they must first be equipped with the central health capabilities such as the cognitive and emotional skills. Indeed, even if one accepts Nussbaum's list of ten central capabilities, it can be argued that whether one can acquire and exercise many of the central capabilities such as having good bodily health, using one's senses and imagination and think, experiencing emotions, depends on whether one has the 'deep psychological states and processes required for one's internal conditions, e.g. one's neural network is in order, that is brain's functions are efficient, rapid, durable and reliable'.[589] Therefore, it is arguable that HGE should only be used in the circumstances when otherwise the child would be born with severe neurological impairment. This argument is in line with the well-being threshold principle suggested earlier which provides that children should be born with certain threshold of well-being assured by the basic capabilities.

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[588] Matteo Mameli, 'Reproductive Cloning, Genetic Engineering and the Autonomy of the Child: The Moral Agent and the Open Future' (2007) 33 Journal of Medical Ethics 87.

[589] Mark Stephen Pestana, *Moral Virtue or Mental Health?* (New York: Peter Lang Publishing 1998).

In the following, I further exemplify how these distinctions may guide policy making in relation to HGE by considering some of the genetic conditions that have become a target of research for potential clinical application in the future.

- Policy implications: some examples from current research

I argue that the notion of basic/central health capability approach suggested by Ruger has, with some refinement, practical implications in the HGE-related policy in that it can provide the "thresholds" needed for deciding and limiting the potential clinical use of HGE: it helps to answer the question whether a certain form of genetic disease/condition would be an appropriate target of HGE and can exclude contentious application. Though at the moment the purported acceptable use of HGE focuses on the prevention of *serious* heritable diseases, it is observed that what amounts to "serious" remains ambiguous, leaving the decision making about what diseases should be selected for the clinical use of HGE 'potentially arbitrary'.[590] I suggest that the concept of central health capabilities within the health capability paradigm can help delineate what may fall under the category of "serious" genetic diseases. The early onset diseases that cause severe neurological impairment which are deemed affecting the central health capabilities can and should be the appropriate target of HGE application. Following this, as I show below, some of the grey areas, which cannot be solved by the existing approach such as the open future principle (see again Chapter 3), can be clarified by adopting the health capability approach which focuses on the central health capabilities.

It may be worth starting by revisiting scientist He's research where he applied HGE to create babies with genetic resistance from contracting HIV disease (see Chapter 1) to illustrate the functionality of the health capability approach in the context of HGE. Previously in Chapter 3, I argued that the open future principle fails to adequately consider whether the implementation of HGE in scientist He's affair is ethically justifiable from a child-centred perspective. Following Ruger's approach and considering the circumstances where scientist He carried out the experiment, it is possible to argue that the implementation of HGE at this stage where the

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[590] Erika Kleiderman, Vardit Ravitsky and Bartha Maria Knoppers, 'The "Serious" Factor in Germline Modification' (2019) 45 Journal of Medical Ethics 508, 511.

uncertainties about the implication for the genes are still substantially high is likely to have unnecessary health effects on the twins. The twins could have been born healthily without being subject to HGE (and thus securing the health capabilities). More importantly, even if the technique is considered safe and effective, it is also doubtful whether HIV disease could validly fall within the permissible threshold (which concerns the central health capabilities) under Ruger's redefined framework. This is because HIV does not cause severe neurological impairment and is manageable with medicine and it can be prevented from birth if it concerns the transmission of HIV from the mother.[591] In short, it is arguable that HIV disease does not affect the central health capabilities. I emphasise again that due to the distinctive feature of HGE (there might be unknown, potentially long-term health effects; the potential or actual risks fall not only to the resulting children but also their descendants),[592] it is only the basic health capabilities that should justify the clinical use of HGE.

Another potential candidate for the use of HGE which is quite controversial is the case of cystic fibrosis. Cystic fibrosis is a life-threatening single-gene disorder which causes respiratory disease that further causes mortality or other morbidity.[593] There has been different views on whether cystic fibrosis should be considered an appropriate target for HGE with the advocate arguing that that cystic fibrosis is one of the most severe heritable condition with 'an extremely burdensome condition' with potential need for lung transplant and other complications[594] while the opponent pointing out that the quality of life of individuals with the such a disease is 'comparable to that of healthy controls'.[595] Using the reframed version of Ruger's central health capabilities as a guide, it is arguable that cystic fibrosis should not fall within an appropriate target of HGE as it will not affect the central health

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[591] World Health Organisation, 'HIV/AIDS' (2017) <https://www.who.int/news-room/q-a-detail/hiv-aids> accessed 26 December 2020.

[592] Kyle Brothers, Mary Devereaux and Robert Sade, 'Bespoke Babies: Genome Editing in Cystic Fibrosis Embryos' (2019) 108 The Annals of Thoracic Surgery 995.

[593] For instance, see Connor Lewis, Scott M Blackman, Amanda Nelson and Others, 'Diabetes-Related Mortality in Adults with Cystic Fibrosis. Role of Genotype and Sex' (2015) 191 *American Journal of Respiratory and Critical Care Medicine* 194.

[594] Supra note 592, Brothers, Devereaux and Sade (2019).

[595] Gabriel T Bosslet, 'Parental Procreative Obligation and the Categorisation of Disease: The Case of Cystic Fibrosis ' (2011) 37 Journal of Medical Ethics 280, 281.

capabilities. This is because cystic fibrosis, though is an early-onset disease, does not affect the brain and affected individuals generally have normal cognitive capacity.[596] There are evidence that medical therapies for cystic fibrosis have increased significantly the lifespan of affected individuals and that since the disease does not affect cognitive function, affected individuals could still be able to make life choices autonomously throughout the disease process.[597] Following the capability approach, they are still capable to carry out life plans, albeit these life plans may be different from other individuals without the disease.

It is worth also considering whether deafness and blindness should be a suitable clinical target of HGE since there are scientists who conducted research on editing genes in human eggs with the aim of altering deaf genes[598] and editing the human embryos to prevent inherited forms of blindness.[599] Following the notion of central health capabilities, I argue that deafness and blindness should not fall within an acceptable use of HGE for the very same reason stated above – that they do not affect the cognitive function of the resulting children. Children born with deafness or blindness would still be capable to facilitate many other capabilities. The potential risks of HGE cannot be outweighed here since the targeted use does not relate to the central health capabilities. The same goes for late-onset diseases such as Huntington's disease,[600] unlike the open future argument (see Chapter 3) which cannot determine if the affected individual would have an open or a closed future, Ruger's refined approach is able to provide guidance. It is likely that late-onset diseases may *not* fall under the criteria set under the central health capabilities framework because the affected individuals would have the basic capabilities for other capabilities and still be able to have a quality life although they may have a shorter life.

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[596] Ibid.

[597] Ibid, 283.

[598] Supra note 53, Cyranoski (2019).

[599] Rob Stein, 'New US Experiments Aim To Create Gene-Edited Human Embryos' (*NPR,* 1 February 2019) <https://www.npr.org/sections/health-shots/2019/02/01/689623550/new-u-s-experiments-aim-to-create-gene-edited-human-embryos?t=1628291664838&t=1628949199670> accessed 14 August 2021.

[600] Heidi Ledford, 'CRISPR Babies: When Will the World Be Ready?' (*Nature*, 24 June 2019) <https://www.nature.com/articles/d41586-019-01906-z> accessed 14 August 2021.

4.3 Conclusion: Summary

While there is a wide acceptance of the health-related reproductive use of HGE, there is yet an appropriate framework in the ethico-legal debate on HGE to justify and further limit such proposed use. This risks "children" and "health" being used as a tool by the stakeholders to obscure the potential harm caused by the uncertainties of the technique. Therefore, having a solid theoretical framework in place is essential to better safeguard the interests of future children (particularly, their interests in developing basic capabilities), to understand why health may be more ethically justifiable than other uses of HGE, and for the policymakers to further assess the proposed clinical use of HGE in light of different genetic conditions. In this chapter, I introduced the capability approach to the context of HGE. The gist of the capability approach is the real opportunities or choices that one has in making decisions in life. I highlighted the general features of Sen's and Nussbaum's capability approach – "capability" and "functioning" are different but closely related; and that there are certain capabilities which are deemed more fundamental than others giving them more of ethical weight.

I also explored how the capability approach is relevant in the context of HGE where future children will inevitably be involved. I pointed out that since the capability approach is outcome-oriented, it is in principle suitable to cover "future children". I argued that the capability approach offers a comprehensive theoretical ground that focuses on children's capabilities in being children and becoming future adults. Next, the capability approach also offers a philosophical and conceptual ground in justifying the health-related use of HGE. Lastly, the capability approach goes further by providing an evaluative framework in addressing the issue of which "health-related" use of HGE is more acceptable in clinical use.

While the capability approach does position children (including the future children) in a place where their interests can be adequately considered and safeguarded in the context of HGE, having such an approach is insufficient to address the problems and gaps in the current debate identified in Chapter 3. Thus, in the next chapter, I explore the concepts of "identity" and explain how a thorough understanding of these concepts can help clear the overall debate on HGE.

Chapter 5 – Different Concepts of "Identity" in the Heritable Genome Editing Debate

In Chapter 4, I filled one of the gaps in the current debate of HGE identified in Chapter 3 – that is, a lack of a suitable framework to explain and further limit the existing proposal for a health-related use of HGE – by exploring the capability approach. In this chapter, I deal with another gap highlighted in Chapter 3: there is a lack of detailed analysis on the concept of "identity" which renders the overall debate vague and sometimes confusing ("the 2nd gap"). A comprehensive examination of the concepts of identity can help to address the 2nd gap by clarifying the complex relationship between genetics and "identity" and how different accounts of "identity" will bring different implications to the ethico-legal debate on HGE.

This chapter begins by setting out justifications for why an identity-based approach may be helpful to the HGE debate and especially from a child-centred perspective. It then provides an overview of the concepts of "identity", examining those that are most relevant to HGE, namely genetic identity, numerical identity, qualitative identity and narrative identity. It then discusses the applicability of the concepts of "identity" to genetic intervention done before birth. Drawing from existing arguments on the mitochondrial replacement technique ("MRT"), technically also a form of heritable editing, this chapter explores how "identity" may be applied to preconception (and preimplantation) genetic intervention. This discussion is crucial to my thesis as it demonstrates the relevance and significance of the concepts of "identity" to the HGE debate. Acknowledging that there are different concepts of "identity" is, however, not sufficient for a comprehensive discussion on HGE. It is also important to understand that these various "identities" are connected to each other, although they may each carry different weight in the ethico-legal debate on HGE. Accordingly, this chapter argues for a multi-faceted concept to identity to better capture the distinct yet interrelated notion of identity. As I shall show, this understanding can help clear the confusion on the issues involving "identity" in the HGE context.

5.1 Justifications of An Identity-Based Approach to the Heritable Genome Editing Debate

As explained earlier, one of the main features of HGE is that the procedure involves editing the genes of the gametes (sperms or eggs) and/or early human embryos. Thus, such a procedure takes place before birth; or to be more accurate, before implanting the embryos into a woman's womb. I argue that the concept of "identity" may be more adequate in such a context than other concepts, for instance, the principle of informed consent, which is more relevant to the discussion relating to existing individuals.[601] As I shall explain below, there are three reasons why the concept of "identity" has a distinctive role in the HGE debate which deserves our attention.

5.1.1 "Identity" and its potential implications for the HGE debate

One of the essential questions in the HGE debate is that whether the modification of the genes/genomes of the human gametes or early human embryos could bring about a change in who that individual is (that is, an identity change) and if that is the case, whether this is something about which there are grounds for ethical and/or legal concern.[602] In order to answer these questions, it is imperative to understand the impacts of genes/genomes on "identity".

There are several ways in which genome editing may be connected to the "identity" of the individual, depending on which concept of "identity" is discussed. Consider the following examples which show how the term "identity" is interpreted differently in different settings:

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[601] It has been claimed that the application of HGE for reproductive purpose is ethically more problematic compared to genetic editing done on existing patients because the consent to have their genes changed prior to birth cannot be obtained in the former case, unlike the latter. See for instance, supra note 3, Polcz and Lewis (2016) 415. However, this claim is criticised for being implausible because informed consent cannot be deemed relevant in HGE since there is no existing individual (see supra note 466, Scott and Wilkinson (2017) 911) and it is incoherent considering that in other policies affecting future generations (e.g. environmental policy), we do not take the future generations' consent into account. (see supra note 409, Gyngell, Douglas and Savulescu (2017) 507).

[602] Ruth Chadwick, 'Genetic Interventions and Personal Identity' in Henk ten Have and Bert Gordijn (eds), *Bioethics in a European Perspective* (Kluwer Academic Publishers 2001) 339, 343.

Glannon points out, the earlier genetic intervention takes place in the life of a human organism (say at the embryonic stage), the more likely it is to 'determine the identities of a distinct person'.[603]

In another setting, Zeiler writes,

> 'Knowledge of the fact that my genes were changed, when "I" was only an embryo, can matter to my understanding of who I am. I am someone whose genome has been modified, I am someone whose genome has been changed so that I will not develop a certain disease; whatever my evaluation of the event is, it can matter for my self-understanding as a human being—and for at least certain aspects of my identity'.[604]

Also, the European Convention on Human Rights and Biomedicine 1997 ("Oviedo Convention") which bans any genetic intervention that aims to change the genome of the descendants,[605] explicitly promotes as its central aim the protection of the 'dignity and identity of all human beings'.[606]

The above paragraphs each point to a distinct concept of "identity". A discussion on these different concepts of "identity" is therefore necessary in order to determine its ethical weight in the HGE debate; otherwise, the debate about the acceptability of HGE based on "identity" is subject to confusion.

5.1.2 Ambiguities in the current law and policy

An exploration of the concept of "identity" is necessary for the HGE debate due to a lack of certainty in the current law and policy on such concepts. The notion of "identity" is referred to within a few of the major international human rights instruments. For instance, as I mentioned above, the Oviedo Convention aims to

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[603] Walter Glannon, *Genes and Future People: Philosophical Issues in Human Genetics* (Westview Press 2001) 34; see also supra note 330, Wrigley, Wilkinson and Appleby (2015).

[604] Kristin Zeiler, 'Who Am I? When Do "I" Become Another? An Analytic Exploration of Identities, Sameness and Difference, Genes and Genomes' (2007) 15 Health Care Analysis 25, 32.

[605] The Oviedo Convention, Article 13.

[606] Ibid, Article 1.

protect the ‘dignity and *identity* of all human beings’.[607] Another international instrument discussed in Chapter 3 is the Universal Declaration on the Human Genome and Human Rights 1997 which provides that the “human genome” is the common heritage of humanity[608] and asserts that germline intervention is a practice that could be contrary to human dignity.[609] Implicit here is that there is a kind of “identity” needed for protection for humankind, although what is it is not clearly stated in the provisions. In Chapter 3, I argued that an interest in having a genuine “genetic identity” (i.e. an untampered genome) cannot be validly established based on these international instruments. It remains ambiguous as to what “identity” truly entails and how it should be interpreted with future children properly considered and safeguarded, especially in the context of HGE. More clarification and interpretation of “identity” are therefore needed so that society has a clearer idea of what to expect from HGE.

The lack of clarity on the concept of “identity” is not only observed in the international setting, but such a gap is also highlighted by academics in the UK legal and policy realm concerning emerging technologies. Gavaghan describes such a concept as becoming a ‘selective blind spot’ for the regulators or policymakers, especially in the field of neuroscience and genetics.[610] The reluctance of lawmakers to tackle the concept of “identity”, which is possibly due to the complex philosophical issues surrounding the concept, is however seen as ‘highly artificial and effectively impossible’.[611] This is because, as Gavaghan observes, “identity” is a genuine concern for many people in real life and there have been assumptions about the nature of “identity” embedded within many existing laws.[612] One example is the purported right to know genetic origins of individuals born as a result of gamete donation in which the relationship between genetics and “identity” has been a

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[607] Ibid.

[608] The Universal Declaration on the Human Genome and Human Rights 1997, Article 1.

[609] Ibid, Article 24.

[610] Colin Gavaghan, ‘A Whole New... You? ‘Personal Identity’, Emerging Technologies and the Law’ (2010) 3 Identity in the Information Society 423, 424.

[611] Ibid, 424.

[612] Ibid, 427.

central issue prominent to the people involved[613] (further discussion of a right to know in Chapter 6). Hence, Gavaghan encourages the law, particularly those regulating reproductive technologies, to engage more directly with “identity” and its implications in this area.[614] It is worth noting that the “identity” in Gavaghan’s text (one that seems to be more personal and individualistic) is different from the “identity” that was described in the previous paragraph in the international setting (the latter seems to focus on a collective sense of identity). This observation itself flags to us that there are different concepts of “identity” applied in different contexts. Understanding these different concepts of “identity” with their possible interpretations will help to move the debate forward.

Furthermore, a comprehensive analysis on “identity” is necessary as a lack of detailed scrutiny of the concept of “identity” by the law seems to have given policymakers wide discretion to interpret it as they see fit. In recent regulations and policy regarding the clinical use of MRT, which as mentioned is also a form of heritable (germline) modification in principle, the law and policymakers seem to have used the concept of “identity” in a way that serves their policy agenda. If it is agreed that the international instruments are to protect the collective “human identity” as a species as pointed out in Chapter 3, then arguably, “identity” has been interpreted in another way by the UK regulators and policymakers in the context of MRT. One of the grounds leading to the eventual legalisation of the clinical use of MRT[615] is that modifying the mitochondrial genome does not have an identity-affecting effect on the eventual individuals where “identity” here is best understood as the personal characteristics of the individuals.[616] The consequence of such interpretation is that there is too much emphasis on how genetic identity would determine one’s “personal identity” and, unsatisfactorily, it affects the scope of the eventual right to information granted to the individuals born via MRT. I do not go into detail at this stage because in Chapter 6, I will revisit and further explore these identity-related issues arising in the legal and policy sphere in light of the right to

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[613] Ibid, 427.

[614] Ibid, 425.

[615] Human Fertilisation and Embryology (Mitochondrial Donation) Regulations 2015.

[616] Supra note 110, HFEA (2013) para 6.69; Department of Health (2014).

know. Before that, it is essential to provide an overview of the concepts of "identity" – a task undertaken by this chapter.

5.1.3 Children and "identity"

In legal studies relating to children's rights, "autonomy" has been one of the prominent frameworks that dominates the area.[617] Nonetheless, whilst it is hard to consider children to have autonomy in any meaningful sense when they are first born, I argue that it is less contentious to claim that there is certain identity (at least, biological identity or human identity) which every individual owns the moment he/she is born. For instance, an infant or a child can be identified by his/her given name or his/her physical traits. The notion that children have "identity" in this sense can be grounded on the principle of human dignity,[618] understood as inherent to human nature and which cannot easily be dismissed as long as we are all within the 'human family'.[619] From this perspective, every single child (including the new born) can have certain forms of "identity" irrespective of their capacities and capabilities or even consciousness of their own "identity".

Having said this, mere identification in terms of the biological identity or civil identity is not the only relevant "identity" for the discussion concerning children. As discussed in Chapter 4, children are having evolving capacities and capabilities,

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[617] See for instance, Aoife Daly, *Children, Autonomy, and the Courts: Beyond the Right to be Heard* (Brill-Nijhoff 2017) In relation to the child's right to be heard, Daly argues that autonomy should be the focus. Note also, speaking of "autonomy" and children, there is sometimes a tension between prioritising children's autonomy rights and protecting their needs. As part of human rights, children are entitled to have their rights respected (for instance, right to be heard, right to participate) while at the same time children are also entitled to protection from harmful environments or experiences due to their limited (but evolving) capacities. Nonetheless, protection and autonomy need not necessarily be seen as always in conflict, but instead reinforcing each other in that protection is needed for children to be able to develop autonomy and autonomy is needed to ensure protection for children (see Gerison Lansdown and Marie Wernham, *Understanding Young People's Rights to Decide: Are Protection and Autonomy Opposing Concepts?* (International Planned Parenthood Federation 2012) <http://createsolutions.org/docs/resources/IPPFprotection_autonomy.pdf> accessed 26 December 2020). Another issue relating to children and autonomy is that it is not always clear if autonomy rights for children can be realised because children often have decisions made for them or imposed on them (see for instance, Rudi Roose and Maria Bouverne-De Bie, 'Do Children Have Rights or Do Their Rights Have to be Realised? The United Nations Convention on the Rights of the Child as a Frame of Reference for Pedagogical Action' (2007) 41 Journal of Philosophy of Education 431).

[618] Ya'ir Ronen, 'Redefining the Child's Right to Identity' (2004) 18 International Journal Law, Policy, and the Family 147.

[619] Respect for dignity of human family has been mentioned in the Preamble of the UNCRC. In Article 28 relating to the right of a child to education, Article 28 (2) explicitly provides that the school discipline must not go against the "child's human dignity (…)". See also Articles 23, 37, 39, 40 in which the main notion is that child (including disabled child) should be respected for the inherent dignity of human family.

leading to increasing autonomy as they grow. As Cowden observes, 'children certainly form a sense of identity from a very early stage' and hence we may owe a duty to tell the truth of the nature of conception to the child as they deserve the same kind of respect as adults.[620] The concept of "identity" is significant in this setting as it has been argued that "identity" is a critical foundation before one can exercise one's autonomous rights,[621] indicating that "identity" can *facilitate* children's (emerging) autonomy. If this is accepted, it then raises the question of what kind of, and how, "identity" can impact one's autonomy? A thorough examination and unpacking of the different concepts of "identity" can shed light on this issue.

5.2 An Overview of "Identity"

As I have shown, the concept of "identity" connotes many different meanings depending on the context. One of the most common phrases adopted in identity-related literature is "personal identity". Nevertheless, in this thesis, I avoid using the term "personal identity" because it has been used, within and across disciplines, to mean different kinds of "identity". For instance, "personal identity" has sometimes been used to mean numerical-qualitative identity;[622] or narrative identity (more details on these different types of identity below).[623] Not only that but the phrase "personal identity" is also adopted as a more inclusive concept in which it, as a whole, connotes genetic identity, numerical identity and even narrative identity.[624] Before going into details on what these other identities mean, it is worth briefly explaining the concept of "identity" in a more general sense.

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[620] Supra note 390, Cowden (2016) 102.

[621] See for instance, supra note 135, Marks (2002) 122.

[622] See for instance, Ana Paula Barbosa-Fohrmann and Gustavo Augusto Ferreira Barreto, 'Are Human Beings with Extreme Mental Disabilities and Animals Comparable? An Account of Personality' in Visa A J Kurki and Tomasz Pietrzykowski (eds), *Legal Personhood: Animals, Artificial Intelligence and the Unborn* (Springer 2017) 129; and for numerical identity, see supra note 313, Holtug and Sandoe (1996).

[623] See for instance, Jackie Leach Scully, 'A Mitochondrial Story: Mitochondrial Replacement, Identity and Narrative' (2017) 31 Bioethics 37, 39.

[624] Supra note 610, Gavaghan (2010).

On a broader level of understanding, "identity" falls into various categories. First, as implicit in Chapter 3, "identity" can be understood as either a single (as in individual) or collective identity. An individualistic identity concerns identity about our single selves, looking at what matters to each of us (although external factors, for instance, the societal environment one is situated in or one's social responsibility, may influence what matters to us).[625] This understanding of identity may include our civil identity (that is, our unique identification through, for instance, our name, gender, race, age) and our story about ourselves (that is, narrative identity – see below). On the other hand, collective identity connotes group identity, most commonly defined by race, age, sex, nationality, social position and many others.[626] Another understanding of collective identity, which is more relevant to HGE, is the human identity as a whole, as in a species.[627] As a human species, we carry this collective identity so as to be distinguished from other organisms such as the non-human animals.[628]

Another possible category of understanding "identity" is through fixed and dynamic identity. A fixed identity is understood as something stable and static. From this perspective, there are some objective criteria that can define one's "identity". One less controversial example may be that being a human is a fixed identity of ours. A more controversial example may be that our race, ethnicity, sex or nationality is also a fixed identity. It is contentious because first, one may change his/her nationality or even sex; and second, it has been highlighted that being categorised in a group is not a natural given but is socially constructed.[629] Apart from a fixed identity, there is also a dynamic identity where it highlights that our "identity" is what we continually construct and edit throughout life based on dialogues and relationships

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[625] See for instance, Constantine Sedikides, Lowell Gaertner and Erin M O'Mara, 'Individual Self, Relational Self, Collective Self: Hierarchical Ordering of the Tripartite Self' (2011) 56 Psychological Studies 98; Harvie Ferguson, *Self-Identity and Everyday Life* (Routledge 2009).

[626] Russell Spears, 'Group Identities: The Social Identity Perspective' in Seth Schwarts, Koen Luyckx and Vivian Vignoles (eds), *Handbook of Identity Theory and Research* (Springer 2011).

[627] Supra note 486, de Andrade (2010). This understanding of identity can be seen in the author's text.

[628] Ajit Varki, Daniel H Geschwind and Evan E Eichler, 'Explaining Human Uniqueness: Genome Interactions with Environment Behaviour and Culture' (2008) 9 Nature Reviews Genetics 749.

[629] James D Fearon, 'What is Identity (As We Now Use the Word)?' (Stanford University 1999) <https://web.stanford.edu/group/fearon-research/cgi-bin/wordpress/wp-content/uploads/2013/10/What-is-Identity-as-we-now-use-the-word-.pdf> accessed 26 December 2020.

with others.[630] “Identity” is also arguably dynamic in the sense that it is constantly changing due to our nature (e.g. our biological contents in the body are continuously being replaced due to the natural biological development and aging process).[631]

Although it is helpful to have a general understanding of “identity” and of the tensions that they raise, merely distinguishing “identity” into the above categories is not sufficient to clear the “muddy waters” in the overall debate on HGE, especially in terms of their ethical and legal implications. Therefore, in what follows, I introduce different types of “identity” which are the most relevant for the discussion on HGE. These include (1) genetic identity, (2) numerical identity, (3) qualitative identity and (4) narrative identity. In the later section, I also introduce what is called a multi-faceted approach to identity, suggesting that our whole “identity” connotes many different aspects of “identity”. This approach cannot be properly addressed without first understanding the different kinds of “identity”.

5.3. Different Types of “Identity”

5.3.1 Genetic identity

It is worth first explaining what the term “genetic identity” might entail since my thesis focuses on genome editing where “genetic identity” is almost inevitable. “Genetic identity” has been interpreted differently in different contexts.[632] From a literal scientific or biological view, “genetic identity” entails the genes’ structure, their functions or roles.[633] Some scholars distinguish between “genetic identity” and “genomic identity”.[634] This idea is derived from the distinction between “genes” and “genomes” (see Chapter 1). The “gene-genome” distinction is also implicitly suggested by the wording used in the Oviedo Convention. As mentioned earlier and

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[630] Supra note 625, Ferguson (2009).

[631] Giovanni Boniolo and Giuseppe Testa, ‘The Identity of Living Beings, Epigenetics, and the Modesty of Philosophy’ (2012) 76 Erkenntnis 279, 281. “Identity” here is best understood as “qualitative identity”. This will be discussed in the next section of this chapter.

[632] For an overview, see supra note 487, Goekoop and Others (2020).

[633] Maurizio Salvi, ‘Shaping Individuality: Human Inheritable Germ Line Gene Modification’ (2001) 22 Theoretical Medicine 527, 536.

[634] Supra note 604, Zeiler (2007).

in Chapter 3, the Oviedo Convention aims to protect the “genome” of the descendants. The word “genome” was chosen deliberately by the Working Party with the reason that such a word is more ‘comprehensive in meaning’ compared to the phrases “genetic constitution” and “genetic characteristics” and may cover ‘those parts of the genome without any known specific function’.[635] This indicates that there are many other parts of “genes” within the “genome”.

Building upon the discussion in Chapter 1, “genetic identity” focuses on the role carried out by the genes[636] while “genomic identity” relates to the whole or entire set of genetic information from both nuclear and mitochondrial genomes.[637] Understood from this literal viewpoint, it is arguable that any genetic modification directly changes *genetic* identity[638] but its impact on the *genomic* identity remains uncertain. It is this understanding of “genetic identity” based on the distinction between “genes” and “genomes” that creates the current loophole in Article 13 of the Oviedo Convention. Although Article 13 prohibits any genetic modification aimed at changing the *genome* of the descendants, it remains unclear whether a change of “genetic identity” in its literal sense would necessarily connote a change of “genomic identity” as well.

What further complicates the matter is that genetic identity and genomic identity can be understood, as discussed earlier, from an individualistic or collective sense. For instance, each of us can have a (different) genomic identity, that is our whole set of genome, making each of us unique;[639] or if understood collectively, humans can also have a genomic identity in the sense that we as a species have a complete set of genomic information which is different from, say, the genomic identity from

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[635] Supra note 486, Steering Committee on Bioethics (2000) 68.

[636] Supra note 633, Salvi (2001) 536.

[637] Supra note 604, Zeiler (2007) 28.

[638] Supra note 623, Scully (2017) 39.

[639] This can be explained through the concept of genome variations in which it emphasises the differences each of us has in the sequence of DNA. For more details, see Genome News Network, ‘Genome Variations’ (2003) <http://www.genomenewsnetwork.org/resources/whats_a_genome/Chp4_1.shtml> accessed 26 December 2020.

another species (e.g. chimpanzees).[640] Hence, there is a need to take into account these viewpoints to clarify the claim that HGE will (or will not) alter the "identity" of the resulting individual.

Different understandings of "genetic identity" have caused incoherence and ambiguity to the ethical and regulatory debate of HGE. In one instance relating the international efforts to protect the integrity of human species,[641] protecting "genetic identity" has arguably meant "genomic identity" in the collective sense as in the genomes of the whole human species. The more relevant ethical/philosophical question to be considered in this instance is, therefore, how much genetic intervention could be done to the individual to the extent that he/she would still be within the human species. This interpretation of "genetic identity" is not adopted in the context of MRT in the UK. The UK policymakers have adopted a scientific understanding of genetic identity in the regulations relating to MRT whereby the ethical permissibility and legality of the procedures are determined mainly through the general understanding of the functions of mitochondrial genomes (more details below).[642] Additionally, "genetic identity" has been interpreted as "genetic origins", particularly in the debate and regulations on reproduction involving gamete donation.[643] The latter understanding involves knowledge about one's genetic parents and/or knowledge about the mode of conception. In Chapter 6, I examine more closely the issues of how "identity" (including "genetic identity") has been interpreted in the international and UK legal and policy setting in light of a right to know. I will show that different interpretations of "genetic identity" carry different legal and ethical implications to the regulations of HGE. It is more complicated when other types of "identity" are also involved in the discussion. I now continue with an overview of other types of "identity" here.

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[640] Supra note 628, Varki and Others (2008); see also, SJ Sholtis and JP Noonan, 'Gene Regulation and the Origins of Human Biological Uniqueness' (2010) 26 Trends in Genetics 110.

[641] Supra note 456, Division of the Ethics of Science and Technology of UNESCO (1999).

[642] Supra note 110, HFEA (2013); Department of Health (2014).

[643] See for instance, *R (on the application of Rose and another) v Secretary of State for Health and another* [2002] EWHC 1593 (Admin); Ken R Daniels and Karyn Taylor, 'Secrecy and Openness in Donor Insemination' (1993) 12 Politics and the Life Sciences 155.

5.3.2 Numerical identity

In Chapter 3, I pointed out that one of the preconditions for the non-identity problem is based on numerical identity. While I intentionally kept the explanation on numerical identity brief in that chapter, it is now time to further elaborate on this concept to understand its ethico-legal implications on the overall HGE debate. Numerical identity, also known as 'identity across space and time', qualifies one 'to continue to exist through change'.[644] Some of the straightforward examples are that Prince William is numerically identical as the Duke of Cambridge; and that a kidney transplant patient stays numerically the same despite a different kidney.

In the genetics context, it is generally accepted that the numerical identity of those patients who undergo somatic genome editing remain unchanged.[645] Also, through its function of identification, DNA has been used in forensics to identify if the suspect and the criminal is the same individual (therefore, if matched, it can be said that the suspect and the criminal is numerically the same individual).[646] This being said, it is worth noting that having the (almost) same genetics profile does not necessarily mean there must only be one individual. For instance, DNA testing has also been used in parenthood testing to identify if *two* individuals are genetically related.[647] In this instance, there are two numerically distinct individuals. Another example is the case of identical twins; even though they generally share the same genes, it is undeniable that they are two different individuals.[648]

Numerical identity deals with the persistence issue; that is, what does it take for an organism to continue over time despite changes. Hence, if we want to know whether one's numerical identity has been altered after or during certain incidents (for

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[644] Supra note 320, DeGrazia (2005) 264.

[645] Niklas Juth, 'Germline Genetic Modification, CRISPR, and Human Identity: Can Genetics Turn You into Someone Else?' (2016) 2 Ethics, Medicine and Public Health 416, 418 & 420.

[646] Sheelagh McGuinness, Bert-Jaap Koops and Eva Asscher, 'Editorial: Genetics, Information and Identity' (2010) 3 Identity in the Information Society 415, 416.

[647] Supra note 604, Zeiler (2007) 28.

[648] Aaron Simmons, 'Do Embryos Have Interests?' (2012) 9 Bioethical Inquiry 57, 60; Christine Hauskeller, 'Genes, Genomes and Identity. Projections on Matter' (2004) 23 New Genetics and Society 285.

instance, going through the genetic modification process), we must be able to answer the former question.

- *The persistence issue: A brief overview*

There has been extensive debate on what makes an organism continue to exist over time despite undergoing some changes.[649] Noting that there is no consensus reached on the persistence question, I identify three approaches in determining numerical identity, namely (1) the psychological approach, (2) the bodily approach (these two approaches are more dominant in philosophical writing); and (3) the epigenetics approach which is arguably more relevant to genome editing. This part of the chapter only provides a brief overview of these different approaches. Although I do not take a stance on which of these accounts is favourable, the discussion here can help us to achieve a better understanding of the concept of numerical identity in general and later assess its weight in the HGE ethico-legal debate.

Starting with the psychological approach: the primary notion is that there should be a psychological connectedness or psychological continuity[650] before and after the changes for one object to be considered the same over time.[651] John Locke first placed emphasis on one's memory to account for psychological connectedness – for one to link the individual one was then to the individual one is now.[652] An example cited was that a 10-year-old child is still numerically the same when he turns 25 years old. Following the psychological connectedness understanding, there is a continuity of states that link the 25-year-old with the 10-year-old rendering "them" the same individual because the 25-year-old carries the memory when he was younger.

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[649] For an overview of this topic, see, for instance, David DeGrazia, *Human Identity and Bioethics* (Cambridge University Press 2005).

[650] Note, these two phrases connote slightly different meanings. See for instance, Eric Olson, 'Personal Identity' (Stanford Encyclopaedia of Philosophy 2019) <https://plato.stanford.edu/entries/identity-personal/#UndPerQue> accessed 26 December 2020, part 4; see also ibid, 16.

[651] Ibid, Olson (2019).

[652] Ryan A Piccirillo, 'The Lockean Memory Theory of Personal Identity: Definition, Objection, Response' (2010) 2 Inquiries Journal.

Nonetheless, this approach which is based on the capacity for consciousness has been questioned for excluding individuals in a vegetative state, individuals with cognitive conditions (for instance, one with dementia or Alzheimer's disease) or even a new born for the reason that there might be a lack of continuing mental contents on these individuals. This is problematic because many (if not all) of us would consider an elderly person who is in a coma or suffers dementia now is still the very numerically same individual he/she used to be.[653] This is where the other account steps in. The bodily approach, or sometimes known as the somatic approach or animalism, connotes the idea that one is numerically the same (one exists) as long as the body remains or persists.[654] This understanding would indicate, for instance, that one who has dementia is still numerically the same as before the condition because his/her biological life remains the same (even if he/she may not be deemed as a "person"[655]); also one who is in a coma is numerically the same as his/her biological body continues to live.[656]

At this point, one may question the applicability of these two approaches in the context of HGE where it inevitably involves editing of the genes of gametes and/or early embryos. Following this, another more recent perspective is worth noting and may be helpful in consideration of numerical identity changes during embryonic development.

This approach is called the 'epigenetics approach' which is an epigenetics understanding of identity, formulated by Boniolo and Testa.[657] In simple terms, epigenetics explains how our genes interact with the molecules within our body and it decides how much or whether some genes are expressed in different cells in our

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[653] Eric Olson, *The Human Animal: Personal Identity without Psychology* (Oxford University Press 1997).

[654] See for instance, supra note 649, DeGrazia (2005); see also Stephan Blatti, 'Animalism' (Stanford Encyclopaedia of Philosophy 2019) <https://plato.stanford.edu/entries/animalism/#OurPer> accessed 26 December 2020 for a detailed discussion on the bodily approach of personal identity.

[655] This understanding of "person" includes a person who must have psychological capability or capacity to consciousness. For a detailed explanation, see for instance, supra note 649, DeGrazia (2005) 11-76.

[656] Ibid, 74.

[657] Supra note 631, Boniolo and Testa (2012).

body.[658] Epigenetic factors are also influenced by the external environment, including our diet and habits and epigenetic changes may then contribute to how one's genes are being expressed. As regards the persistence problem, Boniolo and Testa argue that for a living being to stay the same over time, it depends on the continuity of the epigenetic mechanisms that start since the zygotic (or embryonic) stage.[659] Accordingly, as long as the process of epigenetics continues to take place, one is considered to be numerically the same. Nevertheless, it is worth noting that there is evidence available suggesting that environmental factors have a major role in inducing epigenetic changes in embryos' development.[660] In other words, the developmental stages of the embryos including the development of organs and brain are influenced by the epigenetics process that happened before birth.[661] Thus, it remains unaddressed whether these epigenetic changes that occur prior to birth would affect the resulting children's numerical identity.

As indicated earlier, this part of discussion simply informs the reader of the existing debate on numerical identity and it does not take a position on which approaches better fit. The focus of my thesis is to examine the potential ethico-legal impact of numerical identity in the context of HGE. Therefore, the more relevant question for further examination is how would changing (or not changing) one's numerical identity affect the legal and/or ethical debate relating to HGE. In particular, it is worth looking at the following issues. First, what degree of genetic intervention would amount to a change of the individual's identity to be so different that he/she is now a different individual? Second (and more important to this thesis), how does this affect our ethical and legal decision making in practice? I will revisit these questions in the later part of this chapter.

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[658] For a more detailed understanding of epigenetics, see for example, supra note 282, Simmons (2008).

[659] Supra note 631, Boniolo and Testa (2012) 285 & 289.

[660] Chiao-Ling Lo and Feng C Zhou, 'Environmental Alterations of Epigenetics Prior to Birth' (2014) 115 International Review of Neurobiology 1.

[661] Ibid.

5.3.3 Qualitative identity

Qualitative identity focuses on the aspects of one being constant to oneself (instead of being different from others).[662] Two objects having the same qualitative identity indicates that two of these objects share similar properties or features.[663] One example may be cloning: in principle, clone A and clone B are qualitatively identical but not numerically identical (they are two different subjects although they share the same features). An identical twin may share very similar genes[664] and thus arguably having the same qualitative identity, yet they are clearly two numerically distinct individuals.[665] Qualitative identity changing means changing an “aspect” of the individual (instead of changing the whole individual).[666] As the literature shows, this “aspect” may be taken literally as a feature or property of the individual (e.g. hair, heart, kidneys, etc.), or it may be understood as the impact on the individual after certain procedures. I now elaborate on this with some examples.

The Nuffield Council on Bioethics (“Nuffield”) claims that many medical interventions are already qualitative-identity-affecting compared to the situation if the treatments had not occurred.[667] For example, a patient who suffers from severe kidney failure where the kidney can no longer carry out its role of removing excess fluids and waste products from the body will face life-threatening complications when waste products build up in the body. When and after this patient successfully undergoes kidney transplantation, the fact that the patient now has a new (different) kidney renders a change of his/her qualitative identity in a literal sense.

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[662] Daniel Sollberger, ‘On Identity: From A Philosophical Point of View’ (2013) 7 Child & Adolescent Psychiatry & Mental Health 1, 3.

[663] Harold Noonan and Ben Curtis, ‘Identity’ (Stanford Encyclopaedia of Philosophy 2018) <https://plato.stanford.edu/entries/identity/> accessed 26 December 2020.

[664] Supra note 604, Zeiler (2007) 29. Zeiler differentiates between approximate and exact sameness, noting that the account of exact sameness is rare even for the case of identical twins considering the external factors influencing one’s behaviour or physical traits like environmental factors and diet. Also, see supra note 466, Scott and Wilkinson (2017) 904-905 where the authors also acknowledge that it is rare for two objects to have exactly the same features, thus they prefer qualitative identity to be comprehended as ‘extreme similarity’ (instead of exact similarity).

[665] Supra note 648, Simmons (2012) 60; Hauskeller (2004).

[666] Nuffield Council on Bioethics, ‘Novel Techniques for the Prevention of Mitochondrial DNA Disorders: An Ethical Review’ (June 2012) para 4.14.

[667] Ibid, para 4.11.

From another view, the *effect* of the new kidney on his/her life now arguably also causes a change of the qualitative identity. This is because the medical intervention, in this case a kidney transplantation, if successful, will inevitably improve the quality of life and life expectancy of the patient[668] (therefore a change of qualitative identity). This view is able to cover one who suffers from a mental health illness in which he/she may not have certain biological parts replaced after the therapy, unlike the kidney patients who have their kidneys replaced. By focusing on the effects of medical therapy, it is arguable that undergoing the procedure may also bring effects so great that it has caused a qualitative identity changed. For instance, in the case of antisocial personality behaviour, one is at a high risk of committing crimes or misuse of drugs or alcohol leading to attempting suicide. This is because of, to state only a few, lack of guilt, lack of control of anger and irresponsible behaviour towards society. One of the common treatments is the mentalisation-based therapy which is a talking therapy aiming to help people manage their issues by influencing how they think and behave.[669] If the treatment is effective in influencing the thought patterns and behaviours of the patient, the life of patient may be dramatically different from before. Thus, it can be claimed that the qualitative identity of that patient has been changed.

Based on the examples discussed, it is then arguable that medical intervention does have an impact on one's qualitative identity, even when the intervention does not involve replacement of a biological part in the individual. In the later section of this chapter, I will discuss whether a change to qualitative identity would be applicable to the procedure done prior to birth and, if so, what would be its legal and ethical implications of the procedure.

5.3.4 Narrative identity

The narrative approach of identity (or simply as "narrative identity") has gained wide attention across different disciplines, including social science and psychology. In its simplest form, narrative identity can be understood as storytelling where it includes

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[668] National Health Service (NHS), 'Treatment: Chronic Kidney Disease' (2016) <https://www.nhs.uk/conditions/kidney-disease/treatment/> accessed 26 December 2020.

[669] National Health Service (NHS), 'Antisocial Personality Disorder' (2018) <https://www.nhs.uk/conditions/antisocial-personality-disorder/> accessed 26 December 2020.

stories conveyed by ‘ourselves to ourselves, ourselves to others and others to us’.[670] Following this, there are two ways to describe one's narrative identity, which is from a personal and/or third-party perspective. Since one’s narratives can be formulated based not only on one’s own interpretation (or in Nuffield’s term as “self-conception”),[671] but also on others’ understanding about ourselves (what Nuffield calls it – ‘intersubjective personal identity’),[672] it is rightly claimed that narrative identity is relational.[673] This understanding also highlights that there are many factors (both from internal and external sources) that can contribute to the formation of one’s narrative identity. Hence, the construction of own narrative identity is processual and dynamic in the sense that it is a continuing process and this “identity” is frequently in flux as it changes according to time, space and relationality.[674]

Narrative identity is shaped by one’s life experience as well as his/her own genetic makeup or biological characteristics. Life experiences that are usually formed by events that happened in life help construct one’s inner stories. Somers argues that the connectivity of past events would affect one’s narrative development. The past events and the connections from them (Somers calls it ‘causal emplotment’) can be used as a mode of explanation as it explains ‘why a narrative has the storyline it does’.[675] She exemplifies this with – ‘I felt out of breath last week, I really should start thinking about life insurance’ – showing that the past event of feeling unwell links to and may explain her eventual decision of wanting to buy insurance.[676] Following this, it is arguable that one’s genetic makeup or one’s circumstance of birth could be one of the ‘causal emplotment’ in which it helps to explain the

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[670] Supra note 623, Scully (2017).

[671] Supra note 666, Nuffield Council on Bioethics (2012) para 4.7.

[672] Ibid.

[673] Emily Postan, 'Defining Ourselves: Narrative Identity and Access to Personal Biological Information' (PhD Thesis, The University of Edinburgh 2017).

[674] Maria Oles, ‘Dimensions of Identity and Subjective Quality of Life in Adolescents’ (2016) 126 Social Indicators Research 1401; Margaret R Somers, ‘The Narrative Constitution of Identity: A Relational and Network Approach’ (1994) 23 Theory and Society 605, 621.

[675] Ibid, Somers (1994) 616.

[676] Ibid.

relationship between one with another in the family or in the wider society; and thus, one may construct narrative identity from this. This argument will be revisited and its application in the context of HGE explored in depth in Chapter 6.

As mentioned, as well as considering from a first-person perspective, narrative identity is also relational in the sense that one constructs it depending on the social situation one is in and/or based on what others tell him/her about himself or herself. In other words, the relational aspect of narrative identity may be explained via a social model of identity (or, socially mediated identity). This helps explain how one sees his/her own story as plausible by interpreting how the wider society sees oneself. From this perspective, the third-party view ensures coherency between one's own story formation with others' story formation about oneself.[677] Another relational aspect of narrative identity may be understood as how one's social (or group) identity may influence one's narrative identity. It must be noted that a socially constructed individual (narrative) identity is different from "social identity".[678] "Social identity" here means "group identity" and may be understood as categorising oneself in the social context, or in other words, 'tracking one's membership in a group'.[679] The social group one belongs to (for example, the nationality or religious beliefs) may be determined by the defining characteristics of that group. Although one can be ascribed as a member of the group based on his/her own features and thus follow certain behaviour,[680] it is up to the individual to feel and decide the narratives one has with the group.

Therefore, although narrative identity is relational, it must be stressed that one owns the eventual decision whether or not to accept others' views and despite one's position within a social group. For this reason, it is arguable that narrative identity has an instrumental value which relates closely to self-creation, where DeGrazia explains it as deliberate shaping of one's action or life direction.[681] This also

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[677] Supra note 645, DeGrazia (2005) 86.

[678] Supra note 626, Spears (2011).

[679] Michael Hogg, Deborah Terry, and Katherine White, 'A Tale of Two Theories: A Critical Comparison of Identity Theory with Social Identity Theory' (1995) 58 Social Psychology Quarterly 255.

[680] Ibid, 259-260.

[681] Supra note 645, DeGrazia (2005) 106.

indicates that the construction of narrative identity is critical to one's autonomy (in terms of being able to make autonomous decisions). While DeGrazia has focused on the concept of autonomy in his discussion on narrative identity,[682] I would like to stress another concept, that is, the *capability* to autonomy. In Chapter 4, I discussed a theoretical concept called the "capability approach". Drawing from the discussion here and Chapter 4, I will revisit in Chapter 6 how identity, in the context of HGE, can be seen as a central capability in that it further strengthens the resulting individual's autonomy. Since narrative identity has its ethical significance recognised widely in the academic literature and even in the legal realm, it is thus worth exploring in depth the importance of narrative identity and its impact on "children". Hence, also in Chapter 6, I explain the relationship between genetics and *narrative* identity, especially in the face of a right to know in the legal and policy realm and further explore narrative identity in the context of HGE. For now, it is clear that narrative identity is dynamic, and it is processual in the sense that one can form and constantly (and deliberately) alter such identity depending on one's interpretations (based on their experiences, their position in the wider community) and through perception on others' given opinions.

5.4 Applications of "Identities" in Genetic Intervention Conducted Before Birth

So far, I have outlined four different types of "identity" – genetic identity, numerical identity, qualitative identity and narrative identity. At this point, apart from "genetic identity", it may not be entirely clear how these "identities" are applicable in preconception and preimplantation genetic intervention. Therefore, I now briefly consider this issue by taking into account these different kinds of "identity" in such setting. I look at the following questions: first, how would a genetic intervention amount to a change of the individual's "identity"? Second, how does this affect the relevant ethical and legal debate? Since MRT shares some similarities with HGE in the sense both procedures are carried out prior to birth and have the inheritable character (though for MRT, the effects will only be passed down through the maternal line), MRT is chosen for illustration here.

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[682] Ibid.

5.4.1 Numerical identity: Is the resulting individual the same if we edit the genes of embryos or gametes before birth?

In Chapter 3, I established that the non-identity problem applies in the case of HGE because the decision to use HGE itself will determine the existence of the resultant individuals. I also pointed out that the non-identity problem is preconditioned on *numerical* identity. A further discussion on numerical identity is therefore necessary as it brings implications to the clinical applications of HGE. In particular, if it is a "different" child who was born (an identity-change case), then according to the non-identity problem, there is difficulty to argue, based on a person-affecting principle of harm, that the resultant child born has been harmed by the act of HGE.

There are two possible understandings of "identity" that are at stake here and which would influence the ultimate claim of whether there is a change in the numerical identity of the eventual individual born as a result of the genetic procedure. First, the so-called 'identity-over-possible-worlds'[683] is at stake when the time-dependence view – that one's existence (numerical identity) depends on the time and circumstances of one's conception – is adopted. Zeiler observes that identity-over-possible-worlds is concerned when 'I wonder if I would have been different from who I am now, if my parents had married other people' and the answer would have been 'I would not have been different from who I am now, since I would not have existed'.[684] It is this understanding that has led to what I have established in Chapter 3 that HGE is likely a non-identity case because the decision to use HGE (which would involve the procedure of IVF with the selection of egg and sperm for this specific purpose) would cause the existence of the resultant individual.

Another understanding of "identity" is the 'identity-over-time' which focuses on the persistence issue – whether the subject continues to exist over time despite changes.[685] In an earlier statement when Glannon observes that genome editing that happens at the embryonic stage is likely to 'determine identities of a distinct

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[683] For a more detailed discussion on this concept, see Penelope Mackie and Mark Jago, 'Transworld Identity' ((Stanford Encyclopaedia of Philosophy 2017) <https://plato.stanford.edu/entries/identity-transworld/> accessed 31 August 2021.

[684] Supra note 604, Zeiler (2007) 26.

[685] Ibid.

person',[686] it is likely this understanding of "numerical identity" that was in mind. The related question in this instance is how much change can take place, for example via genetic intervention done prior to birth, before changing the "identity" of the individual. The existing ethical discussion on MRT helps illustrate different approaches in answering this question.

It is observed that the two classic philosophical grounds I identified earlier (the psychological and bodily approach) are not commonly adopted by scholars in the context of MRT. Instead, it has been argued that (1) the numerical identity may be changed if a person were to undergo a change that is so significant (in the sense of improving his/her qualitative identity significantly); or (2) there is a change due to cellular or organism continuity.

As highlighted before, there are two distinct procedures that are deemed a form of MRT: one which is called maternal spindle transfer (MST)[687] and the other called pronuclear transfer (PNT).[688] Without following the philosophical approaches discussed earlier, Nuffield has argued that the application of the MRT, be it MST or PNT, may change the numerical identity of the resulting child compared to the child who would have been born without the application.[689] The reasoning behind this is that the resulting child born via MRT will have a life so different from the one who would otherwise be born with mitochondrial disease, which is often devastating, and this makes them two different individuals.[690] This seems to be in line with the position taken up by Juth. Although Juth first argues that germline genetic modification will not produce a numerically distinct individual, he quickly qualifies the statement by alleging that some germline modification could indeed bring *drastic effect* to the extent that the individual has become *qualitatively different* that he ceases to exist.[691] This ground indicates that qualitative identity may affect

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[686] See supra note 603, Glannon (2001).

[687] That is the transfer of nucleus from eggs.

[688] That is the transfer of nucleus from embryos.

[689] Supra note 666, Nuffield Council on Bioethics (2012) para 4.18.

[690] Ibid.

[691] Supra note 645, Juth (2016).

numerical identity as it suggests that if someone's qualitative identity has been significantly changed then the numerical identity will be changed too. Following Juth's reasoning, it seems that HGE for the purpose of preventing rare genetic disease may have significant qualitative-identity-affecting, and thus numerical-identity-affecting, effect. (Note, however, we may ask what constitutes "massive" genetic modification so as to fall into the qualification made by Juth.)

Similarly, Liao also concludes that the application of MRT may have changed the numerical identity of the resulting child in the sense that the procedure will create a new and distinct individual. However, his reasoning differs from the one offered by Nuffield. Liao instead argues that 'a new and numerically distinct individual' will be created whenever there is a disruption on the cellular or organismic continuity on the original eggs or early embryos.[692] This happens, as Liao argues, when the original egg or early embryo (either from the donor or the parent) is deprived of its function to regulate and coordinate various processes – this is where the nucleus of the egg (or nucleus of the early embryo) has been removed for the procedure. Subsequently, a new and distinct person will be created when the parent's nucleus is transferred to the enucleated third-party donor's egg or the early embryo.[693]

This reasoning would lead to a different conclusion when applied in the case of HGE. As Liao argues, based on the above rationale, genetic modification performed on the early embryo does not render a new and distinct person being created because when modifying (instead of removing), say, the nucleus of the embryo, the cellular or organism continuity is not disrupted since the capacity or function of the cell remains.[694] Following this argument, it may be suggested that there is no numerical-identity-affecting impact when carrying out HGE. Also, if we follow the epigenetics approach by Boniolo and Testa discussed earlier, it is arguable that as long as there is continuity of epigenetics processes along with the embryonic development, then there is no change of numerical identity. As Boniolo and Testa themselves admit that

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[692] Supra note 307, Liao (2017) 22-25.

[693] Ibid.

[694] Ibid, 25.

their approach is only an empirical approach,[695] there is no way to clarify whether this claim is preferable or not.

What can be concluded here is that the use of HGE likely constitutes a non-identity case (with an understanding of identity-over-possible-worlds) in that the decision to use HGE will cause an existence of a particular individual who would otherwise not exist (see again Chapter 3): so, it is A who exists due to the decision to resort to HGE; and it will be B who exists without the decision to act upon HGE. A further question can be asked which is related to the identity-over-time: whether the genome editing done on the embryos will render A still A; or that A becomes another individual, C? Following Liao, Boniolo and Testa's reasoning, one can argue that A will still be A because even with the genome editing, the cellular or organism continuity is not disrupted, and that epigenetic process will still continue while the embryo is developing. However, following Nuffield's reasoning, one may then argue that A will become a new individual, C who would otherwise suffer from a genetic disease with devastating effects that he/she would have a totally different life. Despite the possible, different answers to the latter question, it is likely that the non-identity problem arises as long as we agree on the time-dependence view over the identity-over-possible-worlds.

- Implications to the clinical applications of HGE

Although Nuffield claims that the preconception intervention is not necessarily ethically wrong even if there is a change in numerical identity,[696] some scholars have highlighted the ethical implication of numerical-identity-affecting intervention. Whether there is a change in numerical identity with preimplantation genetic intervention is often linked to the discussion concerning the obligations to future individuals. For instance, Liao claims that whether or not a numerically different person has been created may contribute to discussions on whether the child has been harmed (imagine a child is seeking a claim in the future after he/she is born).[697] If a new and distinct individual has been created from the procedure used before his/her

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[695] Supra note 631, Boniolo and Testa (2012) 289.

[696] Supra note 666, Nuffield Council on Bioethics (2012) para 4.14.

[697] Supra note 307, Liao (2017).

birth, it seems that it is difficult, if not impossible, to argue that he/she has been harmed because the alternative for him/her is not to have existed at all. This is based on Parfit's non-identity problem (see Chapter 3). Holtug and Sandoe are of the view that there is no moral difference between an intervention that is identity-affecting or not because being caused to exist can be either harmful or beneficial to the resulting individual.[698]

As I have shown in Chapter 4, a well-being threshold principle focusing on the health capabilities can act as a retort to the non-identity problem, allowing us to take into consideration the well-being of the resultant children. Furthermore, it must be stressed that a child's existence or a child's (numerical) identity only attains social significance once he/she is born. This social significance is facilitated through identity formation, which is closely related to other kinds of "identity" including qualitative and narrative identity (detailed later).

I therefore conclude here that an understanding of numerical identity is needed to better understand the overall claim as to whether HGE is "identity-affecting". But such a concept itself is insufficient to answer the question fully and evaluate whether HGE is ethically acceptable for its clinical use for reproductive purposes, particularly from a child-centred perspective. The ethico-legal debate on HGE will be more comprehensive by taking a multi-faceted concept of identity whereby it emphasises the idea that other types of "identity" should be taken into account simultaneously (more details on this later).

5.4.2 Qualitative identity: Can it be changed preconception or preimplantation?

While the earlier discussion on qualitative identity concerns the case of somatic intervention – that is, medical intervention on existing individuals – one may question if the same can be applied to those interventions done prior to birth. Bredenoord and others suggest that this is possible. In the context of MRT, Bredenoord and others claim that the qualitative identity of the future individual is likely to have changed in the course of modification of the mitochondrial genome because one without a mitochondrial disease will have a 'different life experience, a different biography

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[698] Supra note 313, Holtug and Sandoe (1996).

and perhaps also a different character'.[699] Thus, in HGE, it is arguable that the qualitative identity of the resulting child will be changed after the modification because he/she may have a different life should he/she born with a serious genetic disease (without the use of germline modification).

As regards its ethical implications, it seems that a change in qualitative identity itself carries less moral weight in deciding whether a procedure should be legitimate. Nuffield acknowledges that there is 'nothing ethically troubling per se' for one to have altered his/her qualitative identity;[700] the ethical question should be whether such alteration is likely to bring an adverse impact upon that individual.[701] Nuffield concludes that whether MRT will impact numerical or qualitative identity will not affect the ethical status of the technology because as in the earlier discussion, many other medical treatments are already having these identity-affecting effects.[702] Additionally, as it has been claimed, no individual can in fact maintain the same qualitative identity over time because through development and aging, we all experience change in the sense that we do not carry the same properties with us.[703]

Hence, it may be right to argue that the fact that a treatment or procedure is qualitative-identity-affecting may not be a justifiable ground to consider the clinical application of HGE since this argument is not commonly made to argue against the use of existing treatments (for instance, the kidney transplantation). Suppose HGE can affect the life experiences of the resulting individuals (thus, affecting qualitative identity). In that case, it may be argued that the technology should then only be used in a way that does not bring adverse effects to the individuals that would eventually be born, or at least to ensure that the individual will have an "acceptable" life experience.[704] This presupposition is in line with the capability approach I discussed in Chapter 4, which suggests that health capabilities would provide the

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[699] Supra note 200, Bredenoord and Others (2011).

[700] Supra note 666, Nuffield Council on Bioethics (2012) para 4.11.

[701] Ibid, para 4.12.

[702] Ibid, para 4.11.

[703] Supra note 631, Boniolo and Testa (2012) 281.

[704] See for instance, supra note 233, Green (1997).

individual with the fundamental opportunities for them to make further choices in life and thus a procedure that promotes health capabilities may be deemed ethically permissible. Still, due to the distinctive features of HGE, only central health capabilities should be allowed.

5.4.3 Narrative identity: The impact from one's circumstance of birth and conditions of life

In the earlier discussion, I highlighted that narrative identity construction is continual and always fluid. Past events may be used as a mode of explanation for one's narrative identity. Thus, it is arguable that how one has been conceived constitutes one of the "past events" and may contribute to one's construction of narrative identity. Furthermore, one's quality of life would also influence his/her formation of narrative identity. This is in line with what has been discussed in the MRT context. For instance, Nuffield explains that the use of MRT may affect one's self-conception in the sense that (1) being born via MRT may also contribute to one's self-conception (for instance, as being a product of donor-assisted reproduction)[705] and (2) having a disease may impact on one's own self-conception.[706] Scully explains this as the 'indirect effect' of MRT in which the application of MRT will affect the child's life experience (whether with or without certain diseases). Scully also claims that what is important is the social-mediated (narrative) identity in which the focus is on the social and cultural influence (for instance, how MRT is represented in the public media) and how that may impact the mitochondrial-donor conceived people.[707] Following this, it is not hard to imagine that how the media portrays HGE and how society reacts to such technology may also influence the individuals born via the procedure.

Despite the ethical implications of narrative identity, it is arguable that the current law does not recognise the significance of narrative identity for the mitochondrial-donor conceived individuals because there is currently no right to identifying information of the mitochondrial donor for the resulting children born via this

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[705] Supra note 666, Nuffield Council on Bioethics (2012) para 4.10.

[706] Ibid, para 4.9.

[707] Supra note 623, Scully (2017).

technique. It has been argued that a right to know the identifying information about the mitochondrial donors is not granted in the case of MRT for two main reasons: (1) the mitochondria are not qualitatively important in contributing to the resulting child's personal traits and characteristics and (2) the genes that mitochondria contribute are quantitatively insignificant (only about 0.1%) to establish a genetic connection between the donor and the resulting child.[708] The importance of narrative identity has thus been neglected in the legal and policy debate involving MRT. Instead, a genetic-based account of identity has been adopted (I will revisit this issue in the next chapter). This lesson must be noted and it is important to consider both narrative and genetic identity in the context of HGE (further discussion in Chapter 6).

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So far, I have discussed different concepts of identities including genetic identity, numerical identity, qualitative identity and narrative identity. These concepts are all relevant in contemplating the HGE debate, although they each may assert different weight in the ethico-legal debate of HGE. It is not, however, sufficient to understand these concepts of "identity" as single and separated from each other. Rather, they are interconnected in that a change of a certain kind of "identity" might also cause changes in the other kind of "identity". In the following section, I argue for what is called a multi-faceted concept of identity and show that this approach can untangle existing confusions on "identity" in the current HGE debate.

5.5 A Multi-Faceted Identity: Distinct yet Interdependent Notions of Identity

5.5.1 An Overview

Focusing only on one conception of identity, although helpful, may not achieve the best outcome in the overall HGE debate. This lesson can be learned from the discussion on MRT – it seems that the UK government has adopted a genetic-based account of identity in which the government has focused more on the role of the genes in one's formation of identity (in the sense of one's personal characteristics).

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[708] Supra note 110, HFEA (2013); Department of Health (2014); supra note 111, Appleby (2018).

This has been criticised for not considering the interests of the child and the interests of the mitochondrial donor who has undergone the often-risky procedure (further detailed in Chapter 6).[709] Thus, it is vital to take into account different types of identities in the HGE debate. As the above discussion has suggested, different concepts of identities are interrelated. For instance, a change of genetic identity (in its literal scientific view) may impact narrative identity, so does a change of qualitative identity. In order to render the discussion on HGE more nuanced, it is helpful to understand the concept of a multi-faceted identity.

The main idea behind the multi-faceted concept of identity is not only an awareness of the different concepts of identities (e.g. genetic identity as one facet of one's whole "identity"; narrative identity as another facet) but also to acknowledge, simultaneously, the interactions between these notions of identities. The implication derived from this understanding is that since "identity as a whole" (clarified shortly) is seen as having different dimensions, affecting one facet does not necessarily constitute a change of the "whole identity" even though a changed facet may also influence another facet. Not only that, the change to one facet may be more remarkable at one stage of life and may connote different significance to the individual at different stages of life.

Seeing "identity" as having multiple dimensions is not novel in academia. For instance, Gavaghan advocates a multi-faceted approach to "personal identity" and claims that "genetic identity" is only one aspect of our "personal identity".[710] It is not entirely clear what "personal identity" should mean with a multi-faceted approach considering that (as mentioned earlier) the phrase "personal identity" can be interpreted differently. His writing suggests "personal identity" as numerical identity[711] as well as narrative identity.[712] Watson also maintains that there is a

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[709] Ilke Turkmendag, 'It is Just A "Battery": "Right" to Know in Mitochondrial Replacement' (2018) 43 Science, Technology and Human Values 56.

[710] Supra note 610, Gavaghan (2010) 430.

[711] Ibid, 429.

[712] Ibid, 430.

continually evolving identity constructed through multiple identities.[713] The one evolving identity in Watson's writing is based on one's sense of self (thus narrative identity). Zeiler also introduces what she calls a 'multi-layered concept of identity' in which she argues that genetic and/or genomic changes may but not necessarily define the whole of one's identity.[714] Arguably, she sees one's identity as a whole in a numerical sense when she sees 'whether my whole multi-layered identity is changed to the extent that "I" no longer exist in the sense that "I" have become a different person' as central to the question relating to germline editing.[715]

Given that there may be different understanding for one's "whole identity", there is a need to clarify what this means. In this thesis, I conceptualise "identity as a whole" to indicate a human identity (or species identity). Our human identity comes with multiple aspects including our genetic identity, qualitative identity and narrative identity. The reason I choose this conceptualisation is because, as discussed in Chapter 3, that current international provisions seem to be built on the notion to protect human species integrity. In line with this, DeGrazia points out that what is ethically troubling about altering one's identity is that the alteration would mean changing the core or essence of being human beings.[716] Following this line of thinking, the question that should be asked in judging the ethical permissibility of the use of HGE is whether the technique would cause a change to the individual's human identity (or in other words, human nature). This is certainly not a straightforward task and worth a thesis on its own in that it further raises the question to what extent changes made on genes and/or genomes would render a change in the identity of one being a "human". The more important question for this thesis is how the employment of HGE would impact different aspects of "identity" of the resulting individual, assuming that the resulting individual would qualify as a "human being" even when there has been preimplantation and preconception genetic modification.

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[713] Nick Watson, 'Well, I Know This is Going to Sound Very Strange to You, but I Don't See Myself as A Disabled Person: Identity and Disability' (2002) 17 Disability & Society 509, 511.

[714] Supra note 630, Zeiler (2007) 29.

[715] Ibid, 31.

[716] Supra note 320, DeGrazia (2005).

To sum up, following a multi-faceted concept of identity, modification done on certain genes and/or genomes can matter not only to one facet of the whole identity but also to other dimensions. Thus, a multi-faceted identity proposed here highlights that the different concepts of "identity" are not identical (in the sense that they serve their own definition and understanding by its own), but they can inform each other. Each of the concept of "identity" discussed earlier hence may have different meanings and bring different implications to the legal and ethical debate involving HGE. Affecting one facet of the whole human identity may not necessarily be deemed ethically unjustifiable. Nonetheless, affecting a certain facet of identity would still be ethically significant and deserve our attention, from a child-centred perspective. The latter question is central to this thesis. In particular, I argue that narrative identity should be given comparatively more attention in the ethico-legal consideration on HGE than that accorded to numerical identity, qualitative identity and genetic-based account of identity (see Chapter 6).

5.5.2 Applications of the Multi-Faceted Identity in Heritable Genome Editing

The interactions of different types of identities, which is stressed by a multi-faceted understanding of identity, can be explained as follows. A child born with a genetic disease or not due to the genetic modification done prior to birth may mean a change in the qualitative identity as well as the genetic identity (in the literal sense). Such a change may in turn be important to one's narrative identity: a change of genetic identity and knowledge of such may serve as an interpretative and constitutive tool in the child's developing process; it also serves as an explanatory tool especially when the body shows some unusual symptoms (probably because of some unforeseen off-target effects that have never been discovered before)[717] due to the modification.

Understanding "identity" through a multi-faceted concept of identity will better answer the pertinent question in HGE – if HGE does not change human nature, to what extent is its use ethically justifiable when other identities are affected and how would the change of these "identities" contribute to the overall HGE debate.

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[717] This is likely to happen especially for the very first few families involved in this procedure (as the technology is still considered new though safe enough for clinical applications).

As I show, a multi-dimensional concept of identity can thus contribute to the current HGE debate as (1) it promotes coherence to the debate of HGE as a whole; (2) it avoids conceptual misconnections and concept creep which may otherwise be ethically problematic; and (3) it avoids the allegation of being genetic determinism – a notion widely criticised.

- To promote coherence to the overall discourse on HGE

Coherence here means making sense as a whole.[718] Coherence 'facilitates successful coordination and promotes effectiveness' of action of plans.[719] This is particularly helpful considering the complex nature of the HGE debate. As explained, when HGE is deemed safe for clinical setting, it will involve several necessary steps in the reproduction. First, the procedure will be done before the child is born, that is the modification is to be done on the reproductive cells or the embryos. Subsequently, there will be implantation of the modified embryo into the woman's womb and it will grow into a foetus. Next, if everything goes as planned, there will be a live birth. When this child has grown up and reproduced, the modified genes will be passed down to the next generations. Hence, it seems that HGE inevitably involves different categories of children and as I argued in Chapter 1, all of these deserve attention in the debate. A multi-faceted concept of identity can inform the debate by taking into account all three categories of children and thus promotes coherence to the debate involving HGE if we see the debate as a whole.

Although each of the "identity" may carry different weight in relation to the ethico-legal implications, they each have a role to play in the debate. As has already been shown, numerical identity can inform the discussion relating to modification done at the stage of gametes and/or embryos as well as future generations. On the other hand, qualitative, narrative, and perhaps social identity may inform the discourse concerning the actual child born via the procedure. The non-identical yet interrelated accounts of identities may together inform the legal and ethical

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[718] Neil MacCormick, 'Coherence in Legal Justification' in Scott Brewer (ed), *Moral Theory and Legal Reasoning* (Basil Blackwell Limited, 1993); see also Stanford Encyclopaedia of Philosophy, 'Interpretation and Coherence in Legal Reasoning' (2010) <https://plato.stanford.edu/entries/legal-reas-interpret/#WhaConCoh> accessed 26 December 2020.

[719] Ibid, MacCormick (1993).

implications of the use of HGE and influence the eventual policy outcome; this may not be able to be achieved if a single layer of identity were to be adopted. For instance, if the discussion is only based on a narrative-based account of identity, it seems that one may easily dismiss it for the case involving embryos on the basis that embryos do not have capacity to form any narratives. A multi-faceted concept of identity thus highlights that the notions of identity are distinct yet related to each other although each may contribute different weight or implication to the legal and/or ethical debate.

- To avoid conceptual misconnection and concept creep

Conceptual misconnections happen when the speaker expresses something with a particular meaning in mind, but this is interpreted as another meaning by the audience, though both of the meanings adopted by the speaker and the audience can be right in their own disciplines.[720] This is likely to occur when the concept of "identity" is understood as one single facet and when there is a lack of consciousness that there are different aspects to them which ultimately form the whole identity. This is because when the concept of "identity" is taken as a single conception, one may then adopt whatever meaning he deems fit in his own field or whatever meaning is available within his knowledge realm. Even when different conceptions are noted, confusion may still occur if there is no clear assignation of what "identity" means in the context. Hence, adopting a multi-faceted concept of identity in the discussion may avoid unnecessary confusion derived from the understanding of "identity".

Apart from the confusion and a lack of clarity, conceptual misconnections can also lead to a scenario called 'concept creep' which is arguably ethically problematic. As Henschke explains, concept creep occurs when "a word that was initially intended to mean concept A takes on concept B" and this is ethically problematic especially when one concept is ethically significant, and the other is not.[721] This is particularly relevant in the discussion involving "identity". As has been suggested throughout the chapters so far, one of the commonly raised arguments in the debate on the use (or

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[720] Adam Henschke, 'Did You Just Say What I Think You Said? Talking about Genes, Identity and Information' (2010) 3 Identity in the Information Society 435, 436.

[721] Ibid, 451.

not use) of germline editing (including HGE) is whether or not genetic modification would affect the "identity" of the children.[722] This may involve different meanings depending on which notion of identity is in mind. Following Nuffield's position, it may not be ethically troubling if "identity" is understood as numerical and/or qualitative identity; however, it may be ethically significant if "identity" is interpreted as "human species" or "narrative identity". Concept creep happens when the word "identity" has been interpreted with another meaning (rather than the claimant's intended meaning) in an argument used in the ethical debate. This may then direct legal policy in ways that are problematic.

- To avoid the trap of genetic determinism

The discussion so far suggests that there is indeed a close relationship between genes and identity. It is however not the case that genes in fact *determine* who we are.[723] A multi-faceted notion of identity sees genetic identity as only one part of one's identity. Although this "facet" can be significant in shaping an individual in terms of some of his/her main features/characteristics, it is not sufficient to define or determine who he/she really is. Therefore, even when much attention has been paid to genetic identity in the discussion of HGE, concerns about genetic determinism can be avoided if a multi-faceted concept of identity were adopted. This is because a multi-faceted identity also considers other aspects of identity such as the qualitative and narrative identity which are built upon both internal and external factors. I will further discuss the claim of genetic determinism in the next chapter.

5.6 Conclusion: Summary

This chapter attempted to bridge the gap in the lack of detailed analysis of "identity" in the current HGE debate, identified in Chapter 3. I argued that, particularly from a child-centred perspective, "identity" is a useful concept in the context of HGE. First, the concept of "identity" is more adequate than other concepts such as

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[722] See for instance, Mark S Frankel and Brent T Hagen, 'Background Paper for Nuffield Council on Bioethics: Germline Therapies' (2011) <https://www.nuffieldbioethics.org/assets/images/Germline_therapies_background_paper.pdf> accessed 26 December 2020.

[723] See for instance, David Resnik and Daniel B Vorhaus, 'Genetic Modification and Genetic Determinism' (2006) 1 Philosophy, Ethics and Humanities in Medicine.

autonomy or informed consent when dealing with germline interventions (including HGE) where interventions occur at the embryonic stage. Second, there is a gap in the current law and policy such that the interpretation of “identity” remains vague, especially in the context of HGE. Third, children can have some form of “identity” despite age and/or physical or mental capacities. It thus raises the question of what kind of “identity” is at stake here and how it would be ethically significant in the context of HGE.

The concept of “identity” cannot be well-explained without understanding that there are different types of “identity”. Thus, I identified four concepts of “identity” which are the most relevant to the HGE debate: genetic identity, numerical identity, qualitative identity, and narrative identity. In order to have a complete and clear debate, I stressed that the discussion on HGE should look at “identity” from these different aspects as a whole. Not only are there different kinds of “identity”, but it is also important to note that some of these concepts of “identity” are *interconnected*. For instance, a change of genetic identity due to the procedure may change the qualitative identity and numerical identity[724] which may further influence one’s narrative and social identity. These two understandings give rise to a multi-faceted concept of identity. The multi-faceted concept of identity that I proposed in this chapter highlights the *interrelationship* between the different types of “identity” in the HGE context and suggests that even if there is a change in certain aspect of “identity”, it need not necessarily be ethically problematic as long as the procedure does not alter human nature. A multi-faceted understanding of identity also explains why a change in certain types of “identity” signifies different ethical weight in the context of HGE. Hence, in line with this understanding, in the next chapter, I further explore the relationship between “genetic identity” and “narrative identity”; and argue that the latter which focuses on the developmental aspect of “identity” should be given more weight than the other concepts of “identity” discussed here in the HGE debate because it better safeguards the interests of the resulting children. I further elaborate on this issue with a discussion on the

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[724] Note, whether there is a change in the numerical identity of the resulting child due to HGE depends on which position to take in understanding what constitutes a change in numerical identity. For instance, as pointed out earlier, following Liao’s argument (see supra note 307, 2017), there may not be a change in numerical identity for a child undergone genetic modification before birth because the function of the particular gene has not been interrupted (unlike the technique of MRT).

development of a right to know “genetic identity” in existing legislation and legal cases in the next chapter.

Chapter 6 – "Identity" in light of a Right to Know and the Role of Capability Approach

In Chapter 5, I provided an overview of the concepts of "identity", including the concepts of "genetic identity" and "narrative identity". I pointed out that "genetic identity" has been interpreted differently in the legal and policy realm. In addition to the discussion in an earlier chapter (Chapter 3), I demonstrated that in the international setting, protecting "genetic identity" has arguably meant "genomic identity" in the collective sense as in the genomes of the whole human species. Nevertheless, this is not the only interpretation available. This chapter examines the other interpretation of "genetic identity" in light of a right to know in the international and UK context, that is as "genetic origins" or "genetic background"; and explores the relationship between this interpretation of "genetic identity" with "narrative identity". I argue that this right to know[725] "genetic identity" is important in the context of HGE because, as this chapter shows, if and when the procedure is legally permitted in the clinical setting, such a right – which emphasises the importance of narrative identity – would adequately safeguard the resultant children's interests.

There are two parts in this chapter. Part I, which serves as a conceptual framework for Part II, begins by examining the development of a right to know in the international context, in particular the position in the United Nations Convention on the Rights of the Child ("UNCRC") and the European Convention on Human Rights ("ECHR"). I highlight how narrative identity which focuses on a developmental meaning of identity has been implicitly recognised by the UNCRC when reading its provisions as a whole; and more explicitly recognised by the European Court of Human Rights as a basis for the right to know one's genetic identity (more precisely, one's genetic background) and as part of the privacy rights. Part I also shows that the legal development of such a right in the international setting has also influenced the legal position in the UK in which a right to know has gradually been recognised in the context of adoption, gamete donation and paternity proceedings with a

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[725] It is worth clarifying here that the terms "a right to information", "a right to know" and "a right to identity" are sometimes used interchangeably in the literature. In this chapter, I refer to these terms interchangeably to mean the same thing. However, as I show, having a right to know/information/identity does not necessarily connote a right to access the information at stake.

considerable attention given to narrative identity interests. It is therefore argued in Part I that there is indeed a strong conceptual basis to claim for a right to know and that this is (and should be) based on a narrative account of identity. Nonetheless, as the discussion shows, a right to know has not been applied uniformly to all kinds of children and that there is a lack of clarity on the nature and substance of this form of identity as currently expressed by the courts, be it in international and UK setting.

Based on the conceptual framework laid out in Part I, Part II defends children's right to know based on the narrative identity interest. It fills the gaps identified in Part I by clarifying what exactly this "narrative identity" should entail and why is narrative identity important in the context of HGE. The main argument for Part II is that prospective children born via HGE should have a right to know that they were born genetically modified. Supplemented by the capability approach discussed in Chapter 4, this line of argument (1) offers valuable insights to how disclosure of this information can act as a safeguard for the resultant children; and (2) also bridges the gap in the current proposal of having a long-term monitoring mechanism as part of a responsible clinical use of HGE in the future (see again Chapter 3).

Part I – A Right to Know "Genetic Identity" in International and UK Context: A Conceptual Basis

6.1 A Right to Know in the International Context

"Genetic identity" has sometimes been interpreted as "genetic origins" that include knowing one's genetic parents and knowledge about one's mode of conception. A child's right to identity in this form has been legally endorsed in several international contexts, including the UNCRC and the ECHR. However, what precisely the right entails is not entirely clear from the current regulatory provisions.

6.1.1 Right to "identity" under the United Nations Convention on the Rights of the Child

The recognition of a right to information for children can be seen in the UNCRC, which is a powerful legal instrument protecting the rights of children.[726] Articles 7 and 8 (discussed more below) are frequently cited for such a right. Although these Articles are more relevant to establishing the civil status of the children,[727] it is arguable that how Article 8 is currently phrased leaves the right to information open for interpretation with the possibility that it includes "genetic identity" (genetic origins). Not only that, as Ronen suggests, if the UNCRC is taken as a whole, it is then reasonable to anticipate its inclination (at least conceptually) towards children's 'individualised identity'.[728] This 'individualised identity' in Ronen's text is consistent with the narrative account of identity (in line with a multi-faceted understanding of identity discussed in Chapter 5) that I am emphasising for the prospective children born via HGE. Thus, as this section shows, reading Articles 7 and 8 together with other important principles such as respecting children's voices enshrined in the UNCRC (Articles 12, 13 – discussed more below) may be a good starting point to consider an expansion of the right to information in light of scientific and technological advances in the reproductive area.

The endorsement of a right to information by the UNCRC is apparent when the United Nations Committee ("UN Committee") expressed concern about the UK legal system where the children did not have the right to know the identity of their genetic parents.[729] Such concern was made in the contexts of a child born to unmarried couple, adoption, and medically assisted reproduction.[730] The UN Committee

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[726] Note that, as Cowden observes, there is disagreement if the UNCRC really can support a right to information in the context of reproductive technologies since the original intention of the drafters was not to entail the technologies: see, supra note 390, Cowden (2016) 91.

[727] Supra note 135, Marks (2002) 123. This is due to the fact that Articles 7 and 8 were introduced at first to tackle with lost children during Argentinean junta (see UNICEF, *Implementation Handbook for the Convention on the Rights of the Child: Fully Revised Third Edition* (September 2007) <https://www.refworld.org/pdfid/585150624.pdf> accessed 25 January 2021, 113).

[728] Supra note 618, Ronen (2004) 160.

[729] UN Committee on the Rights of the Child (CRC), *UN Committee on the Rights of the Child: Concluding Observations: United Kingdom of Great Britain and Northern Ireland* (9 October 2002) CRC/C/15/Add.188 <http://www.refworld.org/docid/3df58f087.html> accessed 29 December 2020, para 31.

[730] Ibid.

recommended that the State party take necessary steps to ensure that all children, regardless of their mode of conception, gain identifying information about their genetic parents as far as possible.[731] This is founded on Article 3 and Article 7 UNCRC;[732] Article 3 (as discussed earlier in Chapter 1) provides that the best interests of children should be 'a primary consideration' in all actions concerning children, while Article 7 provides children a right to nationality and to know their parents. Thus, it seems that the UN Committee has interpreted Article 7 as promoting a child's right to know his/her genetic origins. On this occasion, what is meant by "genetic origins" purportedly includes both the identity of genetic or biological parents and the truth about mode of conception. Although not explicitly mentioned in the provisions, the implementation handbook clearly includes in the implementing Article 7 checklist a consideration of whether children know the circumstances of their birth 'from the earliest date possible'.[733] Arguably, knowing the identity of genetic parents is only effectively guaranteed if the child has first been informed about the mode of conception (more details in later part of this chapter).

It has been suggested that Article 7 UNCRC should be read together with other Articles such as Article 8 of the UNCRC which provides a right to preservation of identity.[734] In Article 8, it is acknowledged that the three aspects explicitly mentioned in the provision – name, nationality and family – are only *some elements of identity*. Identity could include other elements like personal history since birth, physical appearance, gender identity and others.[735] Although "genetic identity"[736] is not mentioned in the list,[737] the use of the word 'include'[738] indicates that the list is not meant to be exhaustive, and it leaves an open gate for interpretation. Thus, it

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[731] Ibid, para 32.

[732] Ibid.

[733] Supra note 727, UNICEF (2007) 111.

[734] Ibid, 112 & 119.

[735] Ibid, 115.

[736] "Genetic identity" here means "genetic origins", which include both the knowledge of genetic parents and the mode of conception.

[737] Supra note 724, UNICEF (2007) 115.

[738] The word "include" is used in the implementation handbook (see ibid, 115) and also in the provision itself (Article 8(1) of the UNCRC).

is a reasonable claim that the current notion of a right to identity guaranteed under the UNCRC can be expanded to involve a right to know one's mode of conception in the era of emerging reproductive technologies.

Other than Articles 7 and 8 which are more specifically related to "identity", the right to identity is also indirectly facilitated by other Articles in the UNCRC. Throughout the implementation handbook, there is a constant reminder that the provisions in the UNCRC are 'interdependent' and the whole convention is not separable.[739] In line with this, Ronen argues that UNCRC provides a conceptual framework with an implicit 'commitment (…) to a dynamic child-constructed identity'[740] by understanding the relationships between Articles 5, 12 and 13.[741] Article 5 emphasises that the state respect parents' and guardians' rights to provide guidance to children in recognition of their evolving capacities (see Chapter 4) in making their own decisions. Article 12 provides a right to be heard (or sometimes also referred to as a right to participation) for the child in that they are free to 'express their views, feelings and wishes in all matter affecting them' and with their views considered and taken seriously.[742] Article 13 provides that every child must be free to express their thoughts and opinions and access all sorts of information. Ronen argues that these Articles indirectly protect and facilitate the children's right to self-constructed identity (i.e. an identity that is according to the child's own wishes, feelings and experience).[743] This resonates with what I am proposing for the prospective children born via HGE, emphasising the narrative identity which captures the developmental meaning of identity. Both of us stress the dynamic nature of "identity" and that children construct their "identity" by themselves but in the social context, be it within a family or within the bigger societal context. Although the UNCRC has not directly addressed the developmental aspect of identity, as I show in

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[739] Supra note 727, UNICEF (2007).

[740] Supra note 618, Ronen (2004) 158.

[741] Ibid, 148 & 160-162.

[742] UN Committee on the Rights of the Child (CRC), 'General Comment No. 12 on The Right of the Child to be Heard' (1 July 2009) UN Doc CRC/C/GC/12.

[743] Supra note 618, Ronen (2004) 160-162.

the next section, the European Court of Human Rights has explicitly recognised such an understanding of identity.

6.1.2 Right to "identity" as part of privacy: Article 8 of the European Convention on Human Rights

The child's right to identity has also been developed as an aspect of our human rights by the European Court of Human Rights ("ECtHR"), whereby the 'developmental and existential meaning of identity' is highlighted.[744] In this instance, the ECtHR considers "identity" as part of one's private life.[745] In particular, the ECtHR has, on several occasions, interpreted a child's right to information as part of Article 8 of the ECHR where Article 8(1) provides for a right to respect one's private and family life. These occasions include proceedings relating to access to childhood files, paternity tests, and access to information about one's genetic parents (discussed more below). These cases affirm that there is indeed a valid concern about children's interests in having access to information relating to their past, thus strengthening the claim for a right to know. Nonetheless, as I show, the current interpretation of a right to information by the ECtHR still leaves a gap for further clarification about the nature and the substance of the identity interest at stake.

I first discuss several cases in order to illustrate how the claim for a right to information has been made and how the ECtHR has acknowledged such a right in the international setting. One of the important cases is the case of *Gaskin v United Kingdom,*[746] which relates to the request for accessing childhood records made by an applicant upon reaching the age of majority of 18. The applicant was received into public care by the Liverpool City Council after his mother died and had been with various foster parents. He claimed a breach of Article 8 ECHR when the local authority refused him access to the majority of the care records of him on the ground of a duty of confidentiality. The ECtHR held that there is a positive obligation on the part of the government to keep and disclose the relevant information to the child

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[744] Supra note 135, Marks (2002) 123.

[745] Yussef Al Tamimi, 'Human Rights and the Excess of Identity: A Legal and Theoretical Inquiry into the Notion of Identity in Strasbourg Case Law' (2017) XX(X) Social & Legal Studies 1, 6.

[746] *Gaskin v United Kingdom* [1989] ECHR 10454/83.

reaching the age of majority. The ECtHR opined that ‘persons in the situation of the applicant have a *vital interest*, protected by the Convention, in receiving the information necessary to know and to understand their childhood and early development’.[747] Following this, such interest thus forms the basis of a right to information, protected via Article 8 ECHR, enforceable by a positive obligation on the local government.

This principle is endorsed by *Mikulic v Croatia*[748] in which the applicant who was born to an unmarried couple had filed paternity proceedings against the potential father identified as H.P. H.P had been avoiding several DNA blood tests under court order. The appeal proceedings had been lengthy. Thus, the applicant lodged a complaint to the ECtHR, claiming that, inter alia, there was a breach of Article 8 due to the excessive length of proceedings. The ECtHR clearly recognised the significance of certainty to one’s ‘personal identity’ for it held that Article 8 was violated when the State did not secure respect for the applicant’s private life by leaving her in ‘a state of prolonged *uncertainty as to her personal identity*’.[749] The ECtHR explained that private life includes ‘a person’s physical and psychological integrity and can sometimes embrace aspects of an individual's physical and social identity’.[750] Referring to *Gaskin*’s case, the Court also acknowledged that ‘respect for private life requires that everyone should be able to establish details of their identity as individual human beings and that an individual's entitlement to such information is of importance because of its *formative implications* for his or her personality’.[751] This reasoning is important as it highlights that it is a human right for one to establish the information regarding his/her own identity and that one’s genetic background can contribute to one’s identity formation.

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[747] Ibid, para 49 (italics are my emphasis).

[748] *Mikulic v Croatia* [2002] ECHR 53176/99.

[749] Ibid, para 66 (italics are my emphasis).

[750] Ibid, para 53. Note, the Court cited the case of *Niemietz v Germany* [1992] ECHR 13710/88 at p 33, para 29.

[751] Ibid, para 54 (italics are my emphasis). Note, the Court referred to *Gaskin v United Kingdom* [1989] ECHR 10454/83 at para 39.

Next, in facing the claim to seek information about her birth, the question that arose in *Odievre v France*[752] was whether the applicant's request for information about strictly personal aspects of a person's history and childhood came within the scope of Article 8. The applicant was placed in the Child Welfare Service after her French birth mother signed a letter at the Health and Social Security Department, indicating her willingness to put the applicant up for adoption. The French legislation allows anonymous births and consent must be requested from the birth mother to disclose her identity. The French authorities therefore did not allow the applicant to have the identifying information regarding her birth mother. The applicant then claimed that French legal system had failed to ensure respect for her private life. The majority of the judges in this case held in the affirmative that Article 8 is engaged – '(b)irth, and *in particular the circumstances in which a child is born*, forms part of a child's, and subsequently the adult's, private life guaranteed by Article 8 of the Convention'.[753] There was, however, no violation of Article 8 as there is a need for the Court to balance the competing interests (which was the mother's interest in keeping the child's birth a secret).[754] The Court concluded that the French legislation is within the margin of appreciation 'which it must be afforded in view of the complex and sensitive nature of the issue of access to information about one's origins, an issue that concerns the right to know one's personal history, the choices of the natural parents, the existing family ties and the adoptive parents'.[755] Although it was held that there was no breach of Article 8 in this case, it clearly demonstrates the value of access to information about one's mode of conception as part of one's identity.[756]

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[752] *Odievre v France* [2003] ECHR 42326/98.

[753] Ibid, para 29 (italics are my emphasis).

[754] Ibid, para 49.

[755] Ibid.

[756] Ibid, see dissenting judgement, para 3. The dissenting judges agreed that 'since the issue of access to information about one's origins concerns the *essence of a person's identity*, it constitutes an essential feature of private life protected by Article 8 of the Convention'. The dissenting judges opined that not being able to access information (though in adoption context) about the family origins is to 'endure a form of suffering' (para 8). What kind of 'suffering' they had in mind was not provided in the reasoning. It may be arguable that it is psychological suffering in which one is left with confusion and uncertainty about his/her own conception. See for instance, Katherine O'Donovan, 'A Right to Know One's Parentage?' (1988) 2 International Journal of Law and the Family 27. The author has identified that one of the needs to know one's parentage is the psychological need for a positive self-development.

The principle that Article 8 ECHR extends to personal identity has also been recognised by the Council of Europe, which has acknowledged that Article 8 protects the ‘right to discover one’s origins’ as an integral part of identity.[757] In particular, in its guide on Article 8 relating to personal development, it explicitly provides that there is a vital interest in getting information to discover the truth about an individual’s personal identity. Not only that this includes information about one’s parents, but it also includes the circumstance of the child’s birth. The latter thus also constitutes part of the child’s and subsequently the adult’s private life protected by Article 8 ECHR.[758] Following this, it is once again affirmed that the “right to discover one’s origins” is to be understood as both being able to know one’s parents and one’s mode of conception.

Although it is promising that the right to know may be safeguarded under the scope of Article 8, there are a few caveats to note. First, as the above discussion suggested, the right is not absolute. Article 8(2) provides limitations for exercising the right to privacy (thus also limiting the right to know which falls within it).[759] Hence, the state may, in certain circumstances, legitimately interfere with such a right. Second, although the ECtHR’s reasoning explored here can establish the relationship between personal development and “identity”, there are still many ambiguities. In particular, the nature and substance in regard to the “identity” at stake here and how this contributes to one’s personal development remains unclear. Tamimi also observes this ambiguity when she sees no explanation and justification offered by the Court on why genetic background is deemed important for “identity”.[760] I shall revisit the ambiguity identified here in Part II of this chapter.

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[757] Council of Europe: European Court of Human Rights, *Guide on Article 8 of the European Conventions on Human Rights - Right to Respect for Private and Family Life* (31 December 2016) <https://www.refworld.org/docid/5a016ebe4.html> accessed 22 December 2020, para 127 (see also para 101 where it is highlighted that ‘private life’ is a broad term and can cover ‘the physical and psychological integrity of a person and can therefore embrace multiple aspects of a person’s identity, such as gender identification and sexual orientation, name or elements relating to a person’s right to their image’); also see para 152.

[758] Ibid, para 127.

[759] For an overview of the possible grounds to limit the rights provided under Article 8(1), see supra note 178.

[760] Supra note 745, Tamimi (2017) 11.

6.2 Legal Development of a Right to Know in the UK

The applications of Article 8 ECHR and Articles 7 and 8 UNCRC to the claim for the rights to know of children has influenced the development of UK law. This can be seen when the UK courts[761] apply the principles, especially in the context of adoption, paternity issues, and gamete donation. However, as I demonstrate, there is, as Frith puts it, an 'unequal application of a supposedly universal right'[762] in that the 'right to know' has not been consistently applied to all children.

The varied application of a right to know can be observed in two instances. First, children born with different assisted technologies have been granted different rights. For instance, there is a right to identifying information about genetic parents for the children born via gamete donation (e.g. through a sperm donor) but this is not the case for children born via mitochondrial replacement technique ("MRT"). How a right to know is *implemented* is also different for adopted children and children born with donor gametes, thus giving them different levels of protection when it comes to a right to identity.[763] Second, even within one type of assisted reproductive technology, for instance, within donor conception, in practice, different children will also have different rights depending on whether parents first disclose the mode of conception to the children – children are able to exercise the right to know if parents choose to tell them the fact, but are unable to do so if parents choose not to disclose the truth.[764] In my thesis, I draw attention to such differences in order to highlight the following matters: (1) the grounds behind the claim for the right to know influence whether a right to know is granted (in particular, how we interpret "genetic identity" influences the claim); (2) even if a right to know is recognised legally (or at least conceptually), it may not be effectively implemented in practice,

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[761] The cases cited here are mainly from the English courts. The legislation in relation to adoption cited later is also only applicable to England and Wales. But note, the Human Fertilisation and Embryology Act 1990 (as amended) which is relevant to assisted reproduction such as IVF with gamete donation applies across the UK.

[762] Lucy Frith, 'Beneath the Rhetoric: The Role of Rights in the Practice of Non-anonymous Gamete Donation' (2001) 15 Bioethics 473, 480.

[763] Ibid.

[764] Ibid, 482. (For a discussion on whether the differential treatment for children born via different methods is justified, see for instance, Ilke Turkmendag, Robert Dingwall and Therese Murphy, 'The Removal of Donor Anonymity in the UK: The Silencing of Claims by Would-Be Parents' (2008) 22 International Journal of Law, Policy and the Family 283, 289-291 where the analogy between adoption and gamete donation has been questioned.)

especially when the decision is left to the parents whether or not to disclose the information to children. These are important lessons to be considered when claiming a right to know in the context of HGE (Part II) and therefore is further discussed below.

In this section, I give a brief overview of how the right to know has been developed in the context of adoption, gamete donation, paternity proceedings and MRT. Since most of these issues involve a third-party involvement,[765] a large part of the claim has revolved around the relationship (and its possible disruption) between the claimant and existing parents with the knowledge of a third party. It is important to note that this relational aspect of a right to know in the context of HGE in the sense of third-party relationship and their identity may not be obvious (since as indicated in Chapter 2, one of the motivations for prospective parents to opt for HGE is to have a healthy child who is genetically related to both of them). However, it is important to recognise that a right to know genetic origins in all these contexts has two aspects – to know the status of conception and to know the identity of genetic parents. The former is important for the latter, and although the latter aspect may not be relevant to the right to know in HGE, one must not dismiss the former which is also vital to one’s overall identity formation. Furthermore, as the discussion shows, the societal attitude towards a particular reproductive method/family planning also has a role in deciding whether there is a right to know for the children (or more precisely, whether it can be exercised by them in practice). As is more apparent in the context of adoption and gamete donation, such practice was initially more commonly kept secret due to the stigma around the practice (thus, the claim for a right to know had been minimal). This is an important observation because it suggests that the societal attitude towards HGE may also play a part in the claim of a right to know for the prospective children.

6.2.1 Right to know in the context of adoption and gamete donation

- Adoption

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[765] In paternity proceedings, a third party is not necessarily involved.

The right to know one's origins has been discussed in two respects in the context of adoption: (1) right to know the status of adoption; and (2) right to know the identity of genetic parents. Historically, the act of adoption was kept secret so as to protect the family from stigmatisation of being infertile or due to the fear of the child wanting to establish a new relationship with the genetic parents.[766] Not only was there a secretive attitude at a family level, i.e. from the adoptive parents, but the secretive attitude could also be seen from the institutional level, i.e., from the government level. The information linking the adoption certificate with the original birth certificate was kept in a special register by the Registrar General and could, on rare occasions, only be disclosed with court's approval.[767] There was also 'forced adoption' in the UK in the 1940s and 1950s for those women who had children outside marriage. This was due to the societal stigma of unmarried women being pregnant.[768] In short, due to the stigma of infertility and illegitimacy surrounding the adoption practice, adoption used to be masked with secrecy in the UK in order to 'preserve certain social standards of morality and normality (…) as well as (…) the reputation of individuals'.[769]

However, there has been a shift of attitude towards adoption since the 1970s, when the legislation governing adoption came under review, including the provisions regarding access to information for the adopted individual.[770] The importance of disclosure of the fact of adoption in the sense of identity was mentioned in the Houghton Committee's report in reviewing adoption law in the UK which states that '(t)his kind of information helps the proper development of a sense of identity, and gives the child and his adoptive parents a fuller understanding of him as an individual with his own unique combination of characteristics, both inherited and acquired from

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[766] Erica Haimes and Noel Timms, *Adoption, Identity and Social Policy* (Gower Publishing, 1985) 12; see also Home Office Scottish Education Department, *Report of the Departmental Committee on the Adoption of Children (Chaired by His Honour Sir Gerald Hurst)* (London Cmd 9248, September 1954) para 22.

[767] Ibid, Haimes and Timms (1985) 12-13.

[768] Manjit Gheera, 'Past Adoption Practices and the Disclosure of Adoption Information' (*House of Commons Library*, SN/SP/6379 October 2014) <https://researchbriefings.parliament.uk/ResearchBriefing/Summary/SN06379> accessed 12 December 2020.

[769] Supra note 766, Haimes and Timms (1985) 77; see also D. Marianne Brower Blair, 'The Impact of Family Paradigms, Domestic Constitutions, and International Conventions on Disclosure of an Adopted Person's Identities and Heritage: A Comparative Examination' (2001) 22 Michigan Journal of International Law 587.

[770] See for instance, supra note 768, Gheera (2014).

his upbringing and environment'.[771] While this statement clearly denotes the value of the information to one's identity formation, it is worth noting that by emphasising the influence of both inherited factors and factors acquired externally, it also indicates that the genetic makeup of the child itself is not the only factor that impacts the development of the sense of self.

Openness in adoption is now widely practised and recognised by the English legal system in the Adoption and Children Act 2002. Section 60 allows an adopted person to request a certified copy of his birth record upon reaching the age of 18, except if the High Court orders otherwise. Frith points out that in the case of adoption, the adopted person's rights to know (1) the fact about him/her being adopted and (2) the birth parents' details are now *both* legally protected.[772] This is because the adopted person is issued an adoption certificate (so-called 'long' or 'full' certificate)[773] therefore, is aware of his/her adoptive status.[774]

A child's *general* right to know the truth about his/her past has been acknowledged by Sir James Munby in the case of *Re X (A Child) (Review of Fact Finding in Care Proceedings)*.[775] The main issue in this case was whether there should be a rehearing of all facts made in the care proceedings that originally placed the child (X) for adoption. The birth parents were initially charged for a criminal prosecution for injuries sustained by X but later the prosecutor abandoned the case as there was no case to answer. Thus, the local authority applied for a reopening of the fact finding for the care proceedings claiming that it was in the child's best interests to know the truth about what happened to him. The judge, citing the cases relating to paternity (to be discussed shortly), acknowledged the principle that ascertainment of truth (whatever the truth may be) is best served the interests of the child and is

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[771] Home Office Scottish Education Department, *Report of the Departmental Committee on the Adoption of Children* (Cmnd 5107, October 1972) paras 28, 29.

[772] Supra note 762, Frith (2001).

[773] 'Birth and Adoption Certificate (England and Wales)' (*Deed Poll Office*, 2012-2018) <https://deedpolloffice.com/change-name/law/birth-certificates> accessed 26 December 2020.

[774] Nonetheless, arguably in practice, it may depend on whether the parents give the certificate to the adopted person.

[775] *Re X (A Child) (Review of Fact Finding in Care Proceedings)* [2016] EWHC 1342 (Fam).

in the interests of justice.[776] The Court reiterated the principle underpinning the family justice system whereby it is suggested that ‘this is something that has to be addressed with honesty and candour if the family justice system is not to suffer further loss of public confidence’.[777] However, it must also be noted that the Court also acknowledged that a child’s right to know the truth should sustain unless ‘his welfare clearly justifies the cover-up’.[778] Although the Court did not elaborate on what amounts to a child’s “welfare” here, this suggests that there are instances where it is better for the child not to know. Importantly, the Court also acknowledged that this knowing-the-truth principle is also an ingredient of the rights protected by Article 8 of the ECHR and Articles 7 and 8 of the UNCRC.[779] This implies that the “identity” interest has been taken into account by the Court as well.

- Gamete donation

Similar to adoption, the use of donor gametes for conception in the UK was initially encompassed by secrecy and anonymity. In the 1990s, it was common, at least in the UK, for donors and recipients to remain anonymous and it was advisable for the recipients to keep it a secret. This tendency was probably due to the negative and dismissive societal reactions towards infertility and the use of artificial reproductive technology for conception.[780] As in adoption cases, in cases involving donor-conceived children, the right to know can also be considered as (1) a right to know their genetic parents and (2) a right to know the fact that the child is donor-conceived.[781]

As an effort to ensure the disclosure of the means of conception, a record of the fact of donor conception on the birth certificate was first proposed in 1984 by the

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[776] Ibid, paras 18 and 20.

[777] Ibid, para 30.

[778] Ibid, para 19.

[779] Ibid.

[780] Eric Blyth ‘Access to Genetic and Birth Origins Information for People Conceived Following Third Party Assisted Conception in the United Kingdom’ (2012) 20 International Journal of Children’s Rights 300.

[781] Supra note 762, Frith (2001).

Warnock Committee.[782] However, the proposal was never implemented due to the concern of discrimination towards donor-conceived people.[783] In 2007, a Joint Committee of the House of Lords and House of Commons recommended the use of birth certificates to ensure donor-conceived individuals are aware of the nature of their conception and so as to effectively implement the intention of legislation in removing donor anonymity.[784] Again, this was not implemented by the Government.[785]

As identified by some authors, greater access to information about one's genetic origins and particularly the removal of donor anonymity was influenced by international trends in recognition of children's rights to information and one major case in the UK concerning donor insemination where the donor-conceived child argued for her right to know relying on international human rights law.[786] Due to the public discourse which claimed for a 'child's right to personal identity',[787] the UK Parliament eventually passed the Human Fertilisation and Embryology Authority (Disclosure of Donor Information) Regulations 2004. These regulations provide that non-identifying donor information is to be gathered by the Human Fertilisation and Embryology Authority ("HFEA") and be made available to the donor-conceived person who seeks information from the Register. With effect from 1st April 2005, the

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[782] Department of Health and Social Security, *Report of the Committee of Inquiry into Human Fertilisation and Embryology* (The Warnock Report) (London, Cm 9314, 1984) <http://www.bioeticacs.org/iceb/documentos/Warnock_Report_of_the_Committee_of_Inquiry_into_Human_Fertilisation_and_Embryology_1984.pdf> accessed 26 December 2020, cited in Eric Blyth, Lucy Frith, Caroline Jones and Jennifer M. Speirs, 'The Role of Birth Certificates in Relation to Access to Biographical and Genetic History in Donor Conception' (2009) 17 International Journal of Children's Rights 207.

[783] Ibid, Blyth and Others (2009) 209.

[784] House of Lords and House of Commons, *Joint Committee on the Human Tissue and Embryos (Draft) Bill*. (Volume I: Report, 2007) <https://publications.parliament.uk/pa/jt200607/jtselect/jtembryos/169/169.pdf> accessed 29 December 2020, para 276.

[785] Marilyn A Crawshaw, Eric D Blyth, Julia Feast, 'Can the UK's Birth Registration System Better Serve the Interests of Those Born Following Collaborative Assisted Reproduction?' (2017) 4 Reproductive Biomedicine and Society Online 1, 2.

[786] Supra note 782, Blyth and Others (2009); supra note 780, Blyth (2012).

[787] See Ilke Turkmendag, 'The Donor-Conceived Child's 'Right to Personal Identity': The Public Debate on Donor Anonymity in the United Kingdom' (2012) 39 Journal of Law and Society 58 for an understanding of how the process of claims-making for a right to know has occurred in the UK.

regulation allows access to identifying information of donors (genetic parents) to any donor-conceived individual upon request from the HFEA at or after the age of 18.

R (on the application of Rose and another) v Secretary of State for Health and another[788] is significant in relation to a right to know one's origins because in this case we saw a UK Court recognising such a right based on Article 8 ECHR. The case concerned the rights of children born via artificial insemination by a donor to information about their genetic parents. The applicant brought proceedings against the local authority for failing to establish a system for donor-conceived children to gain information related to their parenthood. Justice Scott Baker acknowledged the flexibility of the concept of private and family life and that respect for private and family life means individuals should be able to establish their own identity as individual human beings including their origins and the chance to understand them.[789] Justice Scott Baker also endorsed the principle in *Gaskin's* and *Mikulic's* that private life 'embraces their physical and social identity and psychological integrity'.[790] As such, the Court held that Article 8 includes the 'right to obtain information about a biological parent who will inevitably have contributed to the identity of his child'.[791] The Court opined that donor-conceived individuals must have 'suffered damage from the current arrangements, both from the secrecy and from having large gaps in their self-knowledge'.[792] From this reasoning, it is undeniable that the Court has recognised the *contribution* that one's genetic background can make to one's identity-forming process.

Thus, the current UK legislation appears to promote non-anonymous gamete donation and access to identifying information to the donor-conceived children. Nevertheless, plenty of literature highlights that a right to know one's genetic parents can only be effectively upheld after the fulfilment of a right to be *told* of

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[788] *R (on the application of Rose and another) v Secretary of State for Health and another* [2002] EWHC 1593 (Admin).

[789] Ibid, para 45.

[790] Ibid.

[791] Ibid, para 48.

[792] Ibid, para 8.

one's mode of conception in the first place.[793] The claim to disclosure or truth telling is necessary in order to render effective the claim to access identifying information about the donors; because without this, a donor conceived person would have no reason (because they do not know they are donor-conceived) to request the information. In other words, the latter claim is dependent on the former claim.[794] It must be noted that the discussion so far has been concerned with information relating to the identity of the genetic parents, not the information regarding one's mode of conception. While most jurisdictions, including the UK, have legally recognised a right to know the identity of one's genetic parents, a right to know one's mode of conception remains a moral right imposing a moral duty on parents to decide to disclose the truth of conception to their children.[795] This leaving-to-parent position was clearly articulated in the 2001 UK public consultation regarding the information to be provided for donor-conceived people.[796]

To date, there is no formalised structure that imposes an obligation to disclose the mode of conception either on parents or on institutions. However, HFEA has taken a proactive approach regarding parental disclosure, advising treatment clinics to encourage patients to be open with their children from an early age about the modes of their conception by providing information regarding the importance of telling and suggestions of the way to tell.[797]

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[793] For instance, see Mhairi Cowden, 'No Harm, No Foul: A Child's Right to Know Their Genetic Parents' (2012) 26 International Journal of Law, Policy and the Family 102, 120; see also supra note 780, Blyth (2012) 311-312; supra note 762, Frith (2001).

[794] Michelle Dennison, 'Revealing Your Sources: The Case for Non-Anonymous Gamete Donation' (2007) 21 Journal of Law and Health 1, 4; also see supra note 762, Frith (2001).

[795] Supra note 762, Frith (2001).

[796] Department of Health, *Providing Information about Sperm, Egg and Embryo Donors: Consultation Document* (London: Department of Health, 2001) para 1.10 <http://webarchive.nationalarchives.gov.uk/20070305223402/http://www.dh.gov.uk/assetRoot/04/01/87/74/04018774.pdf> accessed 26 December 2020, cited by Blyth and Others (2009) (supra note 782).

[797] S.13(6C) of the Human Fertilisation and Embryology Act 1990 (as amended in 2008); see also Human Fertilisation and Embryology Authority, *Code of Practice 9th Edition* (HFEA (27/06/2018) 885, 27 June 2018) <https://www.hfea.gov.uk/media/2609/june-2018-code-of-practice-9th-edition-draft.pdf> accessed 26 December 2020, paras T63, 20.7 & 20.8.

6.2.2 Right to know in paternity proceedings

The right to know one's genetic origins has also been discussed in the disclosure of parentage to children in paternity proceedings. Several cases are selected here to illustrate how the right to know have been considered with the best interests of the child given the greatest weight by the court in conflicts of others' rights under Article 8 ECHR.[798] Nevertheless, ascertainment of truth (and thus a right to know) is not always upheld – there are also cases which highlight the paternalistic nature of best interests in the sense that the courts have come to different conclusions on whether knowing the truth is always in the best interests of the child. The best interests of the child are also influenced by his/her other interests. This section highlights that although it may be arguable that it is in the best interests of the child to know the truth (including the mode of conception as part of their true "genetic" identity), such a principle is subject to challenge for other interpretations on what is best for the child.

- Best interests of the child as priority among conflicting interests of other parties

The courts have increasingly held that a right to know the genetic truth is in the child's welfare.[799] For instance, in *Re T (Paternity: Ordering Blood Tests)*,[800] the mother had sexual intercourse with the applicant and three other men in order to conceive. The applicant applied for an order of DNA tests believing himself to be the genetic father of the child. The Court granted an order for blood tests after considering the conflicting rights between the different parties (the legal and biological parents and the child). The Court acknowledged the principle that in cases of conflicts of rights to respect to private and family life under Article 8 of the ECHR,

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[798] As the legislation – the Children Act 1989 – demands the welfare or paramountcy principle, many of the cases involving children in the UK work from the assumption that the paramountcy principle – that children's welfare automatically overrides the rights of others – will determine the dispute. There has been argument that this principle is incompatible with the rights balancing approach under the human rights law but this will not be discussed in this thesis. For such a debate, see Shazia Choudhry and Helen Fenwick, 'Taking the Rights of Parents and Children Seriously: Confronting the Welfare Principle under the Human Rights Act' (2005) 25 Oxford Journal of Legal Studies 453.

[799] Carol Smart, 'Law and the Regulation of Family Secrets' (2010) 29 International Journal of Law, Policy and the Family 397, 398.

[800] *Re T (Paternity: Ordering Blood Tests)* [2001] 2 FLR 1190.

the child's rights and best interests should be the weightiest consideration.[801] The Court held that the right in question is the child's right to know with certainty his 'true roots and identity',[802] ascertaining that it is in the best interests of the child to know his true identity. Thus, it was held that interference with other conflicting rights was proportionate to the legitimate aim of providing the child the truth of his identity. When it comes to conflicting rights under the same scope (e.g. rights under Article 8 ECHR), this case affirms that the rights and best interests of the child ought to be balanced by the interests of other parties and acknowledges that in most cases, it is likely that the interests of the child be prioritised.[803] What is also important to note from this case is the endorsement by the court that the right to respect for private life under Article 8 ECHR extends to having and developing knowledge about one's identity.

Similarly, it is also acknowledged that 'suppression of truth' may not best serve the interest of the child in *Re H and A (Paternity: Blood Tests),*[804] whereby a husband brought paternity proceedings against his wife for a DNA test to confirm the parentage of their twins. The lower court refused to grant an order for a blood test on the basis that it would disrupt the existing family life. The Court of Appeal acknowledged that 'the interests of justice are best served by the ascertainment of the truth'.[805] As such, it seems that not only a right to know one's genetic parents is crucial to discover one's 'true roots and identity', but such a right is also assumed to best serve the interests of the child, even when wider family life is concerned. This principle has been endorsed by a recent case at the appellate level.[806] As in *Re T* discussed above, the courts stressed the importance of discovering one's 'true

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[801] Ibid, 1197.

[802] Ibid, 1198.

[803] Note: the welfare or paramountcy principle has not been applied by the court, see ibid, para 34 in which it was held that 'For the purpose of this application of blood tests, the welfare of T (the child) is not paramount under Section 1 Children Act, 1989. Instead, one has to apply the test of his best interests, weighing those best interests against the competing interests of the adults who would be affected …'

[804] *Re H and A (Paternity: Blood Tests)* [2002] EWCA Civ 383, para 28.

[805] Ibid, para 29.

[806] In *Anderson (personal representative of William Brian Anderson deceased) v Spencer* [2018] EWCA Civ 100.

roots and identity', but the nature and content of this "identity" are not clarified (discussed more in Part II).

- Paternalistic nature of the best interests of the child

As pointed out earlier, a right to know (even when protected as part of Article 8 ECHR and as for the interests of justice) is not absolute especially when there are conflicting interests with other parties or when there are distinct interests for the children themselves. In *Re F (A Minor) (Blood Tests: Parental Rights)*,[807] the appellant appealed against the decision of a refusal of blood tests on the child. The Court of Appeal acknowledged that the interests of justice of not suppressing the truth might conflict with the interests of the child. Although it was agreed that the child had an interest in knowing the identity of his genetic parents, it was against his welfare to interrupt the existing relationship within the current family unit in which he was physically and emotionally bound. Consequently, the Court of Appeal dismissed the appeal and held that a refusal of blood tests was justified because it had not been shown that the possible advantages from the tests results could outweigh the potential negative effect to the stability of the existing relationship. Thus, there is no doubt that the best interests of the child is likely to be prioritised (even against public interest of justice in promoting trust and honesty). Nonetheless, in terms of conflicts, it is up to the court to decide what is indeed the best interest of the child. Clearly, in this case, the Court put more emphasis on the child having a stable family relationship rather than the interest of knowing the truth. The inconsistency in judging best interests of the child in different settings is also well-illustrated in the case below, although the case is not relevant to assisted reproduction nor paternity proceedings.

Instead of conflicting rights and/or interests between the child and other parties, the case of *Re M (children) (Ultra-Orthodox Judaism: Transgender) (Stonewall Equality Ltd and another intervening)*[808] highlights the concern of own conflicting interests of a child in a particular setting. For the sake of clarity, I explain the case

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[807] *Re F (A Minor) (Blood Tests: Parental Rights)* [1993] Fam 314 (CA), 318.

[808] *Re M (Children) (Ultra-Orthodox Judaism: Transgender) (Stonewall Equality Ltd and another intervening)* [2018] 3 All ER 316.

from the family court level as *Re A (Children) (Contact: Ultra-Orthodox Judaism: Transgender Parent)* (hereinafter referred to as "transgender case").[809] This case concerns an application made by a transgender (male to female) father, who is from an ultra-orthodox Jewish community, for direct contact with her five children after the father left the community and became a transgender woman. Recognising that living in the Jewish community is the family's 'chosen way of life' and that children have a right to preserve this identity under Article 8 of the UNCRC,[810] the family court judge, Justice Peter Jackson (as he then was) held that the transgender father should not have direct contact with her children but only written contact. This was based on the ground that the devastating consequences of the possible exclusion of the children by the Jewish community due to direct contact with their transgender father were so real and great that it must outweigh all the possible advantages of direct contact.[811] Therefore, the Court, after balancing the welfare of the children and the rights of all family members, reached a decision of refusal of face-to-face contact. The Court of Appeal reversed the judgment of the High Court and the case was remitted to the Family Court for reconsideration. The Court of Appeal stressed that the children's welfare should be judged considering the always changing social attitudes and from the view of a more open-minded modern society.[812] The Court then concluded that 'the best interests of these children seen in the medium to longer term is in more contact with their father if that can be achieved'.[813]

Although not directly relevant to the right to know, the transgender case effectively demonstrates the possible tensions faced in considering what amounts to the best interests of children. This case particularly casts a significant impact on what should be considered in the best interests of the children in light of their daily personal development in a discriminatory society. The transgender case also suggests the need to reflect, in the context of HGE, on the possible consequences of disclosing the fact of being genetically modified on the identity formation for children living in a society

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[809] *Re A (Children) (Contact: Ultra-Orthodox Judaism: Transgender Parent)* [2017] EWFC 4.

[810] Ibid, para 185.

[811] Ibid, paras 187-188.

[812] Supra note 808, *Re M (children)* [2018], para 60.

[813] Ibid, para 138.

with a certain belief system. This is in line with the concern about the influence of societal attitudes towards certain technologies and its subsequent implications on the children's right to know. What is also important from this observation is that it highlights the relational nature of "narrative" identity whereby children are constructing their identity influenced by the bigger context, e.g. the cultural, religious, and political influence (see Chapter 5). This shall be taken into account when making a claim for a right to know for the children born via HGE (further detailed in Part II).

What can be observed from the above discussion is that there is a conceptual basis for a right to know based on human rights and (narrative) identity interest. This "identity" interest is generally seen as serving the interests of children, though further clarification is still needed as regards its nature and substance. Whether it is in the "best" interest for children to know in times of conflict (e.g. when disclosure of certain truth would affect interests of the parents or the child's own interest to maintain a stable relationship with existing family) is, however, subject to interpretations and balancing of different interests of themselves or different parties. While a right to know one's genetic origins has been commonly recognised in the context of adoption, gamete donation and paternity proceedings, it is not the case for children born via mitochondrial donation. As I discuss next, the main reason for this difference is the different interpretation of "genetic identity" that grounded the claim for a right to know in the latter context.

6.2.3 Right to know in the context of mitochondrial replacement technique [814]

As mentioned, the claim for a right to know "genetic identity" has also been engaged in the legal and policy debate on MRT in the UK. This section highlights that the UK government in this instance has conceptualised "genetic identity" based on an individualistic genetic-based account of identity, that is a literal scientific understanding of identity based on the (presumed) roles[815] of the genes. There is a

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[814] Parts of the discussion in this sub-section have been included in the article published by myself, Ilke Turkmendag and Kathryn Hollingsworth (see supra note 429 for more details).

[815] Mitochondria are commonly known as energy provider to the cells. However, this is debatable. See for instance, Heidi M McBride, Margaret Neuspiel and Sylwia Wasiak, 'Mitochondria: More Than Just A Powerhouse' (2006) 16 Current Biology 551 where the authors claim that there are extended roles carried out by mitochondria which include directing and controlling of cell cycle that eventually affects body capacity.

lack of consideration on the narrative account of identity, although such account has been recognised in the debate of other areas such as adoption and gamete donations.

The mitochondria debate in the UK involves two main concerns – (1) the justifications for the clinical use of MRT and (2) the status of mitochondria donors (which in turn affects the corresponding right(s) granted to the mitochondria donor-conceived individuals, including a right to know about the donor). It seems that the UK government (and the proponents of MRT) have adopted a narrow interpretation of genetic identity – that is, an understanding of genetic identity based on a literal or scientific perspective. Such understanding connotes that "genetic identity" is derived from one's genes, that is the genes' structure and/or its function.[816] This chapter focuses more on concern (2) as it relates to the right to know.

One dominant ground leading to a right to anonymity for the mitochondria donors (thus no right to identifying information to the resulting children)[817] is based on the perceived influence that mitochondria DNA has on the resulting children's identity. For instance, in the Human Fertilisation and Embryology Authority ("HFEA") consultation process, the HFEA highlights in its advice document to the UK government that the general permissibility of the technique is, inter alia, based on the view of a (presumably) insignificant amount and role of mitochondrial DNA[818] in an individual's overall genetic constitution.[819] Following the advice from HFEA, the UK government views that MRT only replaces the faulty genes in the mitochondria (described as a 'battery pack') with healthy ones and that the technique does not change the resulting individuals' personal features.[820] This form of conceptualisation of the genetic identity in the UK regulatory debates, which focuses on the minimal influence that mitochondria DNA was presumed to have on the resulting children's personal traits, eventually leads to the outcome that the children who are born via MRT having no right to identifying information about the donor. In such an instance,

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[816] Supra note 633, Salvi (2001) 536.

[817] The Human Fertilisation and Embryology (Mitochondrial Donation) Regulations 2015, Regulation 11(c); section 31ZA(2A). Only non-identifying information of the mitochondria donors is allowed upon request.

[818] This view is subject to challenge (see supra note 812).

[819] Supra note 110, HFEA (2013) para 6.69.

[820] Supra note 110, Department of Health (2014) 15.

the narrative identity of the resulting children is arguably not adequately safeguarded since certain key facts are missing or hidden (discussed more in Part II with the notion of authenticity). The consequences arising from such a conceptualisation of “genetic identity” has led to considerable academic debate.

The cardinal criticism to a genetic-based account of identity embedded in the UK government’s reasoning is that there seems to be an inclination to genetic essentialism[821] in the reasoning, in the sense that a seemingly small contribution of mitochondrial DNA does not affect ‘who you are’. Turkmendag describes this as a ‘calculus of genes’ – a form of reasoning based on ‘a percentage of calculation of DNA’.[822] Turkmendag warns that this genetic-nature basis should not be given ‘privileged standpoint’ as to the effect of how human rights are accordingly granted.[823] Wolf also cautions us against the harm of ‘geneticism’, albeit in a slightly different context,[824] where it signifies the use of genetic conceptions to construct and support power relationships where some dominate and others are deemed inferior. This seems to have occurred in the mitochondria debate as the mitochondria donor-conceived children are arguably subordinated to those born as a result of gamete-donor because both of them are granted different rights – the mitochondrial DNA donated by a third party is deemed to have insignificant effect on the resulting person’s overall (narrative) identity and thus the right to know as established in gamete donation is not extended to mitochondrial donor-conceived children. From the perspective of identity, particularly from a narrative-based account of identity, there should be ‘no categorical difference’[825] between children born through

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[821] Genetic essentialism has the tendency to ‘equate human beings with their genes when making sense of their social, historical and moral complexity’. See Ilan Dar-Nimrod and Steven J Heine, ‘Genetic Essentialism: On the Deceptive Determinism of DNA’ (2011) 137 Psychological Bulletin 800, 801.

[822] Supra note 709, Turkmendag (2018) 74.

[823] Ibid, 57.

[824] Susan M Wolf, ‘Beyond Genetic Discrimination: Toward the Broader Harm of Geneticism’ (1995) 23 Journal of Law, Medicine & Ethics 345, 350. The context that Wolf discusses is genetic discrimination due to the advance of genetic tests. The concern is that people will be given labels and thus disadvantaged based on genetic information. Instead of genetic discrimination, Wolf argues that the harm at issue should be deemed as ‘geneticism’.

[825] This phrase is used by Scott and Wilkinson when they examine the differences (if any) between modifying mitochondrial genome and nuclear genome. They conclude that there is ‘no categorical difference’, from the perspective of identity, between mitochondrial and nuclear genome modification in the sense that both types of modification may have a similar impact on genetic, numerical, qualitative, and narrative identity (see supra note 466, Scott and Wilkinson (2017) 904).

different reproduction methods. Also, as discussed in Chapter 5, the use of MRT may affect one's self-conception in the sense that being born via MRT may also contribute to one's self-conception.[826] The need to know, from a narrative identity perspective, is not necessarily because of physical resemblance between genetic parents and the resultant child but, as I stress in line with the courts' reasoning discussed above, because of the possibility of how being born through certain mode (regardless of whether there is a third party involved or not) can be part of one's history that helps make sense of their own life. Following this, I argue that narrative identity, which emphasises the self-construction of identity by children, should be the focus when we consider the prospective children born as a result of HGE (detailed in Part II).

Part II – A Right to Know in the Heritable Genome Editing Context [827]

In the following, I first lay out the conceptual basis for a claim of a right to know in the case of HGE, drawing from the findings in Part I. I then explore the nature and substance of the "identity" underpinning such a right and which is currently left unexplored by the courts when dealing with a right to know/information. Next, I explain why a narrative-based account of identity deserves more ethical and legal attention in the HGE debate, especially when taking a child-centred approach in which I highlight here that narrative identity ought to be one central capability. This is followed by a discussion to further explore how the information of past or genetic origins can contribute to one's (narrative) identity by examining the role that this information has on one's identity formation. Lastly, I consider the possible implementation of a right to know in the context of HGE from a capability approach perspective.

6.3 The Conceptual Basis for A Right to Know for Resultant Children Born via Heritable Genome Editing

In order to plausibly establish the claim for a right to know for the prospective children born as a result of HGE, there is a need first to establish what information

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[826] Supra note 666, Nuffield Council on Bioethics (2012) para 4.10.

[827] Parts of Part II (except 6.6) have been included in the article by myself, Ilke Turkmendag and Kathryn Hollingsworth (see supra note 429 for more details).

is at stake in the context of HGE and the need for disclosure of such information. As indicated in Part I, unlike the cases of paternity proceedings, adoption and third party assisted reproduction, there seems to be no concern about a third party's identity in the case of HGE (at least in the usual circumstances without involving gamete/mitochondrial DNA donation from a third party). Thus, what is more relevant and, as I show, pertinent for the resultant children in the context of HGE is to discover the mode of conception, i.e., the fact that the child has been genetically modified prior to conception. This part of the chapter deals with Ravitsky's observation that there is a lack of discussion on whether the genetically edited individuals would have a right to know that their genomes were edited before birth.[828] It is my position that children born via HGE should have a right to know such information (and thus be free from deception)[829] in that the parents and the governments should not hide and/or distort (or should encourage, either explicitly or implicitly, to do so) the information relating to one's conception.

A right to know can be defended from an empirical basis and/or a conceptual basis.[830] First, a right to know can be defended by assessing empirical data and arguing from the available data that a lack of knowledge or access to certain information harms the individuals.[831] Second, the conceptual approach defends a right to know, irrespective of the presence of empirical data, based on the notion that there is a deprivation of human rights when they are deprived of certain information so important for their developmental meaning of "identity".[832] Since HGE is currently not legally (or ethically) available for reproductive use,[833] collecting (and thereby assessing) empirical data from the children born via the procedure is not feasible. Thus, in my thesis, I defend a right to know the mode of conception (hereinafter

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[828] Vardit Ravitsky, 'The Right to Know One's Genetic Origins and Cross-Border Medically

Assisted' (2017) 6 Israel Journal of Health Policy Research 1, 5.

[829] Jill Marshall, *Personal Freedom through Human Rights Law? Autonomy, Identity, and Integrity under the European Convention on Human Rights* (Martinus Nijhoff Publishers 2009) 135.

[830] Supra note 828, Ravitsky (2017).

[831] Ibid, 2.

[832] Ibid.

[833] Apart from the procedure carried out prematurely with the genetically modified twins born in China (more details, see Chapter 1).

referred to just “right to know”) for the prospective children by taking a conceptual and normative approach. Having said this, where it is appropriate, I also refer to the empirical literature used in other contexts to illustrate and strengthen my claim.

Drawing from the discussion in Part I, at least three (overlapping) grounds are applicable for a right to know for the prospective children born via HGE. First, children’s right to information has gained legal and judicial recognition as part of human rights. In particular, as suggested in Part I, such a right is protected as an aspect of privacy rights through Article 8 ECHR. Arguably, a right to preserve one’s “identity” which includes knowing the details about his/her mode of conception, is also protected under Article 8 UNCRC (read together with other principles in the Convention as a whole). Second and related to the first ground, the international as well as UK law have widely recognised the significance of personal development, including the formation of self-identity. As such, establishing personal identity is seen as part of one’s private life with the formative function of identity also emphasised. Thus, in line with the developmental aspect of identity currently underlined by the courts in cases involving access to information about the past and genetic background as part of human rights, it is plausible to argue for a right to know for children born via HGE with an identity-based ground (though more details are needed as to the nature and content of the “identity” at stake). Third and related to the second ground, the ascertainment of truth is generally seen as a good practice in serving the interest of children.[834] A right to know the truth has, in general, been held to be in the best interest of the child for the positive personal development of the child, including forming his/her own identity. Cowden argues for a right to be told about the mode of conception because ‘deception of this nature constitutes a wrong in that it violates the respect owed to that child’.[835] This is based on the understanding of ‘recognition respect’ which confers respect on children as children and not just the future adult they are becoming.[836] Thus, failing to tell the truth is

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[834] It must be noted that the interests of children need to be balanced with the interests of other parties. In case of conflicting rights and/or interests, the UK Court has held that priority should be given to the interests of the child, this is even true when the public interest of justice is on the other side of the balancing test, see the case of *Re T (Paternity: Ordering Blood Tests)* [2001] 2 FLR 1190; *Re F (A Minor) (Blood Tests: Parental Rights)* [1993] Fam 314 (CA) discussed in Part I of this chapter.

[835] Supra note 390, Cowden (2016) 101.

[836] Ibid, 101-102

morally unacceptable behaviour as 'it fails to respect that child's status as an identity-holding entity'.[837] This position is in line with my orientation in this thesis, especially as shown in Chapter 4 where I explored and applied the capability approach in the context of HGE as such approach takes into account children as both being and becoming.

Drawing from the above grounds, my claims are as follows. There should be a right to know for the prospective children born as a result of HGE on the ground of narrative identity interest. Instead of a genetic-based account of identity as adopted in the MRT debate (see Part I of this chapter), I argue in this thesis that a narrative-based account of identity should be given more ethical and legal weight in grounding such a claim. Acknowledging that there may be conflicting cases where the interest of children knowing this information may be weighed and balanced against interests of other parties (in the case of HGE, most likely the rights of parents), such interest generally best serves the welfare of children and is protected by Article 8 ECHR. The protection of such interest requires disclosing accurate and truthful information about the fact of conception to the children. For the rest of this chapter, I elaborate on a narrative-based account of identity in the context of HGE. In particular, I explain how I conceptualise narrative identity in the context of HGE by laying out the main characteristics of narrative identity. Subsequently, I defend the ethical (and legal) significance of narrative identity derived from getting the information by taking a capability perspective, including a discussion on how narrative identity can be seen as a central capability and the role of the information (that is, the fact of being born genetically modified) on one's narrative identity.

6.4 Conceptualising Narrative Identity in the Heritable Genome Editing Debate

As discussed in Part I, *Gaskin*'s case[838] established that there is 'a *vital interest*, protected by the Convention, in receiving the information necessary to know and to understand their childhood and early development'.[839] Referring to *Gaskin*'s case,

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[837] Ibid, 102

[838] *Gaskin v United Kingdom* [1989] ECHR 10454/83.

[839] Ibid, para 49 (Italics are my emphasis).

the Court in *Mikulic v Croatia*[840] also acknowledged that 'respect for private life requires that everyone should be able to establish details of their identity as individual human beings and that an individual's entitlement to such information is of importance because of its *formative implications* for his or her personality'.[841] As well as in *Odievre*'s case,[842] the dissenting judges, though disagreed on whether Article 8 was violated, agreed that 'the issue of access to information about one's origins concerns the *essence of a person's identity'* and that it constitutes an essential feature of private life protected by Article 8 of the ECHR.[843] While this reasoning highlights that it is indeed a human right for one to be able to establish the information regarding his/her own identity and that one's genetic background (which does not confine to just knowing about one's genetic parents; it could be any information relating to the past) can contribute to one's identity formation, the notion behind this "identity" is left unexplored. In this part, I therefore address the ambiguity left unsolved in the current legal reasoning on the right to know (and/or access to information about one's past) by focusing on the "narrative identity". In what follows, I explore the main features of a narrative-based identity and its significance in the ethico-legal debate of HGE.

6.4.1 The nature of narrative identity

The concept of narrative identity has been applied in various areas, including philosophy, psychology and social science.[844] This thesis calls for attention to several main characteristics commonly referred to as a narrative account of identity. As I first outlined in Chapter 5, narrative identity can be formed via storytelling – we construct own stories to make sense of our life.[845] Although this story is developed

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[840] *Mikulic v Croatia* [2002] ECHR 53176/99.

[841] Ibid, para 54 (Italics are my emphasis).

[842] *Odievre v France* [2003] ECHR 42326/98.

[843] Ibid, dissenting judgment, para 3 (Italics are my emphasis).

[844] For a brief overview of different theories of narrative identity, see Eunil David Cho, 'Narrative Identity' in David A Leeming (ed), *Encyclopaedia of Psychology and Religion* (Springer 2018); Augusto Blasi and Kimberly Glodis, 'The Development of Identity: A Critical Analysis from the Perspective of the Self as Subject' (1995) 15 Developmental Review 404. For social science literature, see supra note 674, Somers (1994); for an understanding of how the theoretical model of narrative identity has been developed, see Dan P McAdams, 'Narrative Identity' in Seth J Schwartz, Koen Luyckx and Vivian L Vignoles (eds), *Handbook of Identity Theory and Research* (Springer 2011) 99-115.

[845] Supra note 623, Scully (2017); also, supra note 666, Nuffield Council on Bioethics (2012) para 4.7.

internally, it is relational in the sense that we construct our story according to not only our own view (first-person perspective), but also third-party perspective (others' perception of us).[846] It is also relational in that external factors affect how we construct our stories as well. Hence, narrative identity is formed through multiple factors, including our life experience, our genetic makeup, our biological characteristics (our qualitative identity), and our civil identity. As these factors are constantly changing, so are our narrative identities. Following this understanding, narrative identity is then processual and dynamic.[847] This understanding is important for making a claim for the right to know for the prospective children born via HGE, particularly in dealing with the claim of genetic determinism and essentialism (discussed more shortly).

It is worth reminding that since self-narrative is relational, it is closely related to social identity which usually goes beyond individual and family and is constructed by social and/or cultural factors. Social identity of a child born genetically modified may be associated with the social image of such act and the resulting individuals, as perceived by the society, which could include the policymakers.[848] As such, if the societal force is negative, it may negatively influence the child's self-conception about being genetically modified (and vice versa). Although this thesis does not consider the current societal attitude towards possible employment of HGE, it is plausible to think that how a child born via HGE perceives himself/herself may be dependent on the existing social environment that he/she has been born. Consequently, it is important to understand the implication of being a child as a result of HGE within the wider societal context. For instance, how the media reports the use of HGE will likely have a plausible impact on the self-conception of the resultant child.[849] In line with this thinking, if the fact of being genetically modified is purposefully kept hidden by parents and the social institution (for instance, the law or the government), it may also influence how one perceives oneself (if the child ever finds out). It is also true that, as I pointed out earlier in relation to how stigma

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[846] Ibid, Scully (2017).

[847] Ibid, Scully (2017); supra note 666, Nuffield Council on Bioethics (2012) para 4.7.

[848] Supra note 766, Haimes and Timms (1985) 77, albeit in the context of adoption.

[849] Supra note 623, Scully (2017), in the context of MRT.

once attached to the practices of adoption and gamete donation, stigmatisation of HGE (if any) may itself lead to non-disclosure of such fact to the resulting children and consequently, may further impact their identity formation (more below).

It is sufficient for now to sum up that this chapter conceptualises narrative identity as such: it is in the form of storytelling and is dynamic. Narrative identity is not over-individualistic when we also consider its relational construction in that it may be influenced by the third-party view and external factors. Since it is relational, it is plausible to claim that narrative identity is *influenced* (but not determined) by many other types of identity, for instance, gender identity, sex identity and even genetic identity (i.e., genetic origins).

6.5 Why Does Narrative Identity Deserve Legal and Ethical Attention? A Capability Perspective

Before explaining why narrative identity (and particularly to the claim of a right to know) should be given greater weight compared to other concepts of identity in the ethico-legal debate of HGE, I must first address the concerns about genetic determinism and genetic essentialism. Juth differentiates these two concepts: the former is defined as the view that 'a person is a product solely of his genes' and other factors such as the environment become less significant. Meanwhile, the latter is the view that genes 'determine the essence of who we are'.[850] These concepts, though phrased differently, carry a common feature: that genes can explain human traits. What is problematic with the essentialism and determinism view is that it connotes excessive reliance on the impact of genes on the formation of human characteristics, thus giving genes 'more causal power than what scientific consensus suggests'.[851] Hence, this notion has been criticised (1) for being contrary to our biological perception of human behaviours (since our behaviours are also influenced by our external exposure apart from genetic inheritance)[852] and (2) for placing far

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[850] Supra note 645, Juth (2016) 418.

[851] Niklas Gericke and Others, 'Exploring Relationships Among Belief in Genetic Determinism, Genetics Knowledge, and Social Factors' (2017) 26 Science & Education 1223, 1224-1225. Also, see supra note 645, Juth (2016).

[852] Wendy Johnson, 'Genetic and Environmental Influences on Behaviour: Capturing All the Interplay' (2007) 114 Psychological Review 423; Anders Nordgren, *Responsible Genetics: The Moral Responsibility of Geneticists for the Consequences of Human Genetics Research* (Kluwer Academics Publishers 2001) 109.

too much emphasis on genes and identity and thus also placing too much value on genetic relatedness, which is out of line with modern notions of family (for instance surrogacy or donor-conception).[853]

As a response to this concern, it must first be remembered that the notion of narrative identity discussed in this chapter should be taken in line with the multi-faceted concept of identity I introduced in Chapter 5. Narrative identity is only one of the aspects of the whole human identity. Narrative identity itself also comes with multiple facets (including genetic background) in which it is constructed by oneself based on what one is telling oneself and what others are telling him/herself. An individual's characters (and hence, his/her narrative identity) are influenced by internal genes' interaction with each other within one's body and the external social and cultural context he/she is living in.[854] The knowledge on epigenetics also explains how gene expressions may change due to interaction with each other depending on the environment one is exposed to.[855] Therefore, it is right when Postan observes that our personal bioinformation is not the only information needed for our narrative construction.[856] Noting this, the claim made in this chapter is thus *not* vulnerable to the criticism that rendering genetic knowledge as vital to one's identity reinforces the notion of genetic essentialism or determinism because my position *does not* suggest that such information of the past (i.e., in regard to the mode of conception) is *sufficient* and *determinative* for shaping of a coherent narrative.

Moreover, and also related to why narrative identity deserves legal and ethical attention, I agree with Ravitsky's view that defending a right to know certain information does not imbue any necessity or preference to that piece of

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[853] Supra note 204, Leighton (2013). (Note, genetic relatedness may be less relevant in the case of HGE if considered in light of the possible claim of a right to know; but it may be relevant when one considers that the goal to go for HGE includes having healthy children who are also genetically related to the prospective parents. In the latter scenario, it is then reasonable to consider if we, as a society, have put too much weight on the value of genetic relatedness which may have somehow contributed to parents wanting to resort to HGE.)

[854] See for instance, National Human Genome Research Institute, 'Human Genomic Variation' (2018) <https://www.genome.gov/27570931/april-06-human-genomic-variation/> accessed 26 December 2020.

[855] Supra note 631, Boniolo and Testa (2012) 284.

[856] Supra note 673, Postan (2017) 81-82.

information.[857] However, only if the piece of information can potentially make a significant difference in one's life is defending such a right meaningful or plausible.[858] As such, attempts to understand ourselves by getting the right piece of information does not devalue other identity-formation contributing factors like the environment, but it justifies one's right in getting that information.[859] In the context of HGE, it is important to focus on the *impact* of this information (the truth of being born genetically modified) rather than the *type* of information (that it is genetic information). From this understanding, my position will not exclude the possibility that one eventually decides to refuse the information as part of his/her identity. I now further consider, from a capability approach, why this deserves ethical and legal attention.

6.5.1 Identity as a central capability

As discussed in Chapter 4, the capability approach emphasises the real opportunities or choices that one has in making decisions in life. Particularly in the context of children, the capabilities of children are dependent on many other personal and social factors. I also highlighted that some capabilities deserve more priority than other capabilities because without them, many other valued capabilities might not be exercised at all in the first place. Whilst in Chapter 4 I argued that health capability is one of these central/basic capabilities, in this chapter I argue that having an "identity", in particular, narrative identity is also one central capability.

Understood from a capability approach, the right to know based on a narrative-based account is important because ensuring such a right may affect many other capabilities of children (including the capability to autonomy). The right to know the truth is an essential condition of being autonomous. This is indicated by Spranzi and Brunet where they argue that everyone should have the freedom to choose bits and pieces and decide which is relevant for them in making sense of who they are.[860]

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[857] Vardit Ravitsky, 'The Right to Know Genetic Origins: A Harmful Value' (2014) 44 Hastings Center Report 5.

[858] Ibid.

[859] Ibid.

[860] Marta Spranzi and Laurence Brunet, 'Personal Identity as a Form of Freedom' (2014) Hastings Center Report 3; see also, supra note 643, Daniels and Taylor (1993) 164 where the authors argue that one should have the right to know about the facts that would have impact on his/her own life.

Phillips also argues that people who do not have a strong sense of identity are not able to 'think reflectively, make choices and plan their lives'.[861] Hence, a right to know is important for children in acquiring accurate information and such knowledge offers real opportunities for one to make informed choice,[862] thus promoting one's autonomy.[863] Such claim for a right to know is based on an understanding that having a narrative identity is a central capability.

Sen himself seems to have acknowledged the importance of narrative identity when he argues that 'in arriving at goals, a person's sense of identity may well be quite central', not only as regards the individual but also on account of how others' goals might shape one's sense of identity and personal goals.[864] Following Sen, Davis sees the capability of being able to sustain a 'personal identity' (which resembles a narrative account of identity) as one 'central freedom'.[865] He asks, 'can individuals … be thought to be free beings if they are unable to generally sustain personal identities over their lifetimes?'[866] He explains, based on Sen's concept of freedom within the capability approach, that the free agent in this context is to be understood as having the freedom to 'carry out one's plans and goals', to 'act and bring about change, and whose achievements can be judged in terms of her own values and objectives'.[867] Comim and Teschl argue that one's ability to reason about his/her values can be impacted by how the individual views him/herself and how he/she can (or cannot) select among multiple aspects of his/her identity.[868] They observe a close

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[861] Anne Phillips, *Multiculturalism Without Culture* (Princeton University Press 2007) 105.

[862] Ann T Lamport, 'The Genetics of Secrecy in Adoption, Artificial Insemination, and In Vitro Fertilization' (1988) 14 American Journal Law & Medicine 109.

[863] See for instance, supra note 623, Scully (2017) 42. Autonomy is termed as self-determination by Scully in which she highlights the ethical significance of narrative identity and its effect on a person's life.

[864] Amartya Sen, 'Goals, commitment and identity' (1985) 1 Journal of Law, Economics, & Organisation 341, 348.

[865] John Davis, 'Identity and Commitment: Sen's Conception of the Individual' (2005) 55 Tinbergen Institute Discussion Paper 1, 25.

[866] Ibid.

[867] Ibid.

[868] Flavio Comim and Miriam Teschl, 'Introduction: Capabilities and Identity' (2006) 13 Journal of Economic Methodology 293, 294.

relationship between one's narrative identity and his/her capabilities, in particular the capability to act as a free agent:

> 'The identity of a person connects her choice of actions and provides a background for her formulation of life-long plans. Her sense of autonomy and responsibility is linked to the possibility of shaping her view of herself as an individual and as a member of her community'.[869]

Freeman argues that there is little force arguing for normative recognition drawing on the concepts of rights until one can pinpoint the 'good' encompassed in the alleged right.[870] The discussion above presents this 'good' required for the claim for a right to know for the resulting children born as a result of HGE. Based on above reasoning, it is arguable that being able to form one's narrative identity is a general capability that is central as it ensures the exercise and expansion of other more particular capabilities such as the capability to make informed decisions. A right to know protects a narrative-based identity interest that is essential for the child to be a free agent[871] both during childhood and adulthood. When the focus is on a narrative-based understanding of identity, this right need not only be relevant where a third party is involved in the assisted conception.

From the literature especially in gamete donation, several interests are being identified as possible grounds to base a claim for a right to know.[872] Two of which are the most relevant in the context of HGE are health/medical interest and identity interest. While I agree that these are two distinct interests, I wish to further highlight in my thesis a point that has been largely overlooked in existing discussion. I argue that these two interests are closely connected when we understand the relational aspect of narrative identity in which health factors (be it physical health or health-related information) impact the construction of one's identity. In the context of HGE,

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[869] Ibid.

[870] Michael Freeman, 'The New Birth Right? Identity and the Child of the Reproduction Revolution' (1996) 4 The International Journal of Children's Rights 273, 276.

[871] Traina contends that children and adults should in general be seen as moral agents who are 'dependent and conditioned' and that agency need not always indicate legal liability for the individuals. See Cristina Traina, 'Children and Moral Agency' (2009) 29 Journal of the Society of Christian Ethics 19.

[872] See e.g. Vardit Ravitsky, 'Conceived and Deceived: The Medical Interests of Donor-Conceived Individuals' (2012) 42 Hastings Center Report 17.

a right to know will allow the resulting children to discover their medical history, monitor their health, and allow them to make an informed decision about their future reproductive choices (since the modifications that they were subjected to may be passed to their descendants). Given that one reason for the clinical use of HGE is to prevent the transmission of a genetic disease, prospective children also deserve to know the medical history that led their parents to use HGE. This, in turn, affects how they construct their narrative identity. Additionally, this right to know is also important to the proposal for a well-structured long-term follow up programme[873] for the resulting children. Realising the fact that they are born as a result of HGE may help them develop their true self, understand the purpose of the follow up programme, and eventually reason and decide whether or not they want to participate in the programme. This resonates with what Eekelaar argues: knowing one's genetic background 'allows the individual to confront the world as it is on his own terms, and influence solutions according to his perception of his interests given the physical truth'.[874] Only when the resultant individuals fully comprehend the need of the long-term follow up, can this programme be fruitfully implemented and achieve its advocated purpose of safeguarding children's health and medical interests. Hence, from this perspective, identity seems to be a capability that helps facilitate other interests such as the medical interests. If it is agreed that being able to develop own's identity is a central capability, it is then essential to understand how certain information such as knowledge of the mode of conception might contribute to one's shaping of identity – something that is missing in the courts' judgement as discussed in Part I.

6.5.2 The roles of information on narrative identity

There are two prominent (closely related) functions of knowing the fact of being genetically modified on children's narrative identity in the context of HGE. First, it promotes coherence – knowing one has been genetically modified before birth is pivotal for the resulting child in developing his/her self-conception and to make sense of his/her own identity (especially considering that the procedure may have unpredictable effects, even when it is safe enough for clinical use). Second, it

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[873] For more details, see Chapter 3.

[874] John Eekelaar, *Family Law and Personal Life* (Oxford Scholarship Online November 2017) 161.

ensures authenticity – if one's self-narrative were built upon false information, one may develop a distorted identity.[875] I briefly explain each of these below.

- *Making sense of who we are*

As suggested, self-conception indicates that one forms narratives based on what story one is telling oneself. That story inevitably depends on what information we have about ourselves. Knowledge of being born genetically modified is vital in contributing (again, not determining) to the child's sense of own identity. This is due to the 'interpretive and structural role' that genetic information can play in making sense of one's identity as a whole.[876] The knowledge of our circumstance of birth is considered as our past or personal history. Thus, it can be the 'sources of meaning in one's life' and 'to deny our past is to be false to ourselves'.[877] This information of the past helps to connect the dots and justify why we take certain actions.[878] In the case of HGE, due to the complexity of epigenetics process,[879] there may be some impact to the body which have never been discovered before, even when HGE is deemed safe and effective to be used. Apart from health and safety concerns to individuals and the population, such a piece of information is so important for the individual child's identity formation, especially when the body is experiencing some unusual conditions due to the genetic modification done prior to birth. Such analogous situation may be illustrated by the memoir of Susannah Cahalan which captured the moments where she had suffered a loss of mind, body, and self-identity. Cahalan was frustrated at being unable to make sense of everything about her own unusual behaviour due to false information given to her about her state of condition months before she was finally diagnosed with a rare brain disorder.[880]

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[875] Jeffrey Bluestein, 'Choosing for Others as Continuing a Life Story: The Problem of Personal Identity Revisited' (1999) 27 The Journal of Law, Medicine & Ethics 20, 23.

[876] Supra note 673, Postan (2017) 41.

[877] Joseph Raz, *Value, Respect and Attachment* (Cambridge University Press 2001) 33.

[878] Supra note 674, Somers (1994) 616. See discussion in Chapter 5 (section 5.3.4).

[879] See for instance supra note 282, Simmons (2008).

[880] Susannah Cahalan, *Brain on Fire* (Penguin Group 2014). For a quick reading, see Carole Cadwalladr, 'Interview: Susannah Cahalan: 'What I Remember Most Vididly are the Fear and Anger'' (*The Guardian*, 2013). <https://www.theguardian.com/books/2013/jan/13/susannah-cahalan-brain-fire-interview> accessed 26 December 2020.

Although not relevant to HGE, the personal experiences by Cahalan have well-captured the importance of getting the truth, or the consequences of not being able to know the truth about one's body, in making sense of own identity.

Furthermore, a lack of information relevant to forming one's identity has caused psychological and emotional disturbance and this has been supported by plenty of research, particularly in the context of adoption and donor-conceived reproduction. The term 'genealogical bewilderment' has been commonly cited by many proponents for a right to know to emphasise the condition of being in confusion and doubt in ways that negatively affect adopted persons' psychological health due to a knowledge gap about one's origins.[881] In addition to a lack of knowledge, accidentally discovering the truth about own birth and/or knowing the truth only during adolescence has also been argued to cause 'psychological disturbance'.[882] It is crucial to be cautious about over-generalising the reasons one may seek for certain information.[883] It is also important to note that it is subjective for each individual to digest and process life experiences. So, what an adopted person or a donor-conceived person has felt does not necessarily mean a child born genetically modified will feel the same. However, the empirical research here provides support for the significance of a right to know to the individual's (narrative) identity formation.

- *Authenticity*

Authenticity can be loosely defined as being true to ourselves.[884] Authenticity closely relates to coherency in my previous point. Being "true" to ourselves can be seen in two aspects. First, it relates to self-determination, which may be understood as

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[881] Supra note 794, Dennison (2007); see also supra note 643, Daniels and Taylor (1993). Both cited HJ Sants, 'Genealogical Bewilderment in Children with Substitute Parents' (1964) 37 British Journal of Medical Psychology 133.

[882] See supra note 766, Home Office Scottish Education Department (1954) paras 22 & 150 where Hurst Committee points out the importance of telling an adopted person as early as possible his/her adoptive status to avoid a varying degree of psychological disturbance.

[883] Caroline Jones, 'The Identification of 'Parents' and 'Siblings': New Possibilities under the Reformed Human Fertilisation and Embryology Act' in Julie Wallbank, Shazia Choudhry and Jonathan Herring (eds), *Rights, Gender and Family Law* (Routledge, 2010) 222; see also Jane Fortin, 'Children's Right to Know Their Origins – Too Far, Too Fast?' (2011) 21 Child and Family Law Quarterly 336, 338.

[884] For a detailed overview of "authenticity", see Somogy Varga and Charles Guignon, 'Authenticity' (Stanford Encyclopaedia of Philosophy 2020) <https://plato.stanford.edu/entries/authenticity/> accessed 26 December 2020.

being the author of our life as we define ourselves and are in control of our stories.[885] Second, it relates more closely to self-realisation in line with the idea that 'there is a true or real you already inside yourself waiting to be discovered or uncovered'.[886] Knowing the real us thus directs us 'to realise' what we already are.[887] It is the latter that I am concerned with in the context of HGE. As observed by Marshall,[888] it is also this definition that seems to have been adopted by the European Court of Human Rights in its reasonings in cases including *Gaskin*'s case,[889] *Mikulic*'s case,[890] and *Odievre*'s case[891] discussed earlier.

Living an authentic self needs accurate information and such living has been seen as closely related to personal autonomy in that one discovers, defines and is responsible for one's own life (one's actions) (discussed more below).[892] Bluestein also points out that for narrative to be identity-constituting, it must be highly coherent – that it must be genuine and in sync with what others' view oneself.[893] Inaccurate beliefs about the past may also undermine the individual making sense of their physical and social environment, therefore compromising his/her capacity to create a trustworthy autobiography.[894] Lillehammer observes that although everyone may be aware that there are some knowledge gaps in that some facts about our genetic origins are unknown to us (e.g. our distant biological relatives; some of our ancestors), there is another scenario that is ethically problematic: having information based on the 'false

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[885] Supra note 829, Marshall (2009) 99.

[886] Ibid.

[887] Ibid.

[888] Ibid, 123.

[889] *Gaskin v United Kingdom* [1989] ECHR 10454/83.

[890] *Mikulic v Croatia* [2002] ECHR 53176/99.

[891] *Odievre v France* [2003] ECHR 42326/98.

[892] Diane Meyers, 'Decentralising Autonomy: Five Faces of Selfhood' in John Christman and Joel Anderson (eds), *Autonomy and the Challenges to Liberalism: New Essays* (Cambridge University Press 2005) 27-55.

[893] Supra note 875, Bluestein (1999) 23.

[894] Lisa Bortolotti and Ema Sullivan-Bissett, 'The Epistemic Innocence of Clinical Memory Distortions' (2018) 33 Mind & Language 263, 263; see supra note 673, Postan (2017) 83.

belief that one's knowledge of these origins is accurate or complete'.[895] It is 'wrong' because it involves a 'false consciousness' that keeps the individuals from their genuine interests 'in the service of the interests of others'.[896] This can be illustrated by the character of Krystal Goderitch in the TV series Orphan Black.[897] Goderitch is a cloned subject but not aware that she is. She lives as a manicurist. The monitoring process was done on her in secret. She however always felt that something was not right around her and later falsely believed that it was the corrupted beauty industry that conducted testing of cosmetics on humans. In such an instance, it is arguable that Goderitch may think that she is pursuing her real interests, but in fact her living condition is constrained and essentially serving the interests of others (e.g. the scientists who carried out the cloning and purposefully hid the fact from her). Although fictional, this character clearly demonstrates what Bluestein suggested – that living with false or misleading information risks having a distorted identity.[898] Thus, information about being genetically modified prior to birth should be truthful for the resulting children.

After establishing why narrative identity deserves ethical and legal attention and the roles of information in identity development, it is also worth considering whether the right to know proposed here can be implemented. The capability approach, as shown in Chapter 4, has also been a useful theoretical tool in understanding the practical implementation of the formal rights of children (e.g. those enshrined in the UNCRC). Hence, I argue that the capability approach can also offer us insights on whether (and in what ways) the right to know proposed here can actually be realised.

6.6 Possible Implementations of the Right to Know in Heritable Genome Editing Context: An Explanation from the Capability Approach

Apart from the nature and content of narrative identity, it is also useful to understand the nature and scope of the right to know itself. I argue that a right to

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[895] Hallvard Lillehammer, 'Who Cares Where You Come From?' in Tabitha Freeman and Others (eds), *Relatedness in Assisted Reproduction: Families, Origins and Identities* (Cambridge University Press 2014) 106.

[896] Ibid, 107.

[897] *Orphan Black* (2013-2017).

[898] Supra note 875, Bluestein (1999) 23.

know could be seen as a negative or a positive right, or even both negative and positive respects to it. In this sense, the right to know can be interpreted as forbidding some forms of intervention and requiring the execution of certain actions. For instance, as a negative right, the right to know I proposed in this chapter might protect children against active deception or secrecy on purpose. As a positive right, it might connote the child's claims to receive this information or having access to it (that is, to be told of the nature of their conception; or to grow up with such a knowledge). While negative rights are usually asserted against everyone, most positive aspects of the right especially in the context of HGE would likely be claims against the child's parents or the government.[899]

Using the capability approach, there are two ways to address whether the proposed right to know in the context of HGE can be realised in practice. First, it can be argued that health capabilities (which focus on the abilities and freedom to achieve health)[900] can ground the actualisation of the proposed right to know for the prospective children born via HGE. The central health capabilities (those health capabilities which are fundamental for other capabilities)[901] are essential for one to realise or exercise the right to identity proposed in the chapter. The proposed right to know, which mainly draws on the development of narrative identity, is only practical if one has the ability to access and use the information (the mode of conception) and this is influenced by his/her relative capabilities. It is valid to question whether a person born without the basic health capacities would have the ability and freedom to exercise the right, whether or not it is legally enforced. Hence, as discussed in Chapter 4, to ensure the actual exercise of rights, it is also important to foster human basic capabilities (here, the health capabilities). This idea is consistent when we are taking a child-centred approach. It is plausible to argue that children should be equipped with the basic capabilities so that they can actualise many rights given to them, including the right to know.

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[899] Supra note 374, Millum (2014), albeit the text is written in the context of a right to an open future.

[900] For more details, see Chapter 4.

[901] Ibid.

Second, the capability approach also allows one to consider many other factors that affect the capabilities to actualise this right, e.g. whether the right is legally enforced or ethically enforced. In this instance, it is then essential to look at the societal and political structure. Bearing this in mind, an individual's position in a particular social setting may constrain one's capabilities even though he or she has been equipped with the central health capabilities.[902] For instance, as may have been illustrated in the transgender case discussed earlier, the children's interest in having contact with their genetic father (who later became a transgender woman) was arguably overlooked on the basis that the children were living in a society with certain form of discriminatory attitude towards transgender. The later decision by the Court of Appeal to reverse earlier judgement – that there should be no direct contact between the children and the father – seems to have delivered the message that stigma should not be a legitimate reason to deprive children's interests (and/or rights – put in the context of HGE, a right to know). Noting the possible impact of societal or political influence on the actual implementation of a formal right, it is worth to now further elaborating on the possible implementations of a right to know for the children born genetically modified.

As indicated in Part I of this chapter, there is currently no definite structure which legally enforces a right to be told the mode of conception, although, in the case of donor-conception, the government has explicitly encouraged the treatment clinics to advise parents to tell the truth to the children as early as possible. Consequently, the question arises is whether there is a way to ensure parental disclosure to the child about the fact that they are genetically modified. Based on the debate on adoption and donor-conceived children, a few possible implementations of a right to know for the resultant children from HGE can be imagined, including (1) granting access to health record at the age of majority; (2) granting a birth certificate with such status; and (3) promoting good practice to disclose the truth by advising the prospective parents to do so and at the same time, taking steps to monitor and reduce possible social stigma around the use of the technology. It is worth briefly

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[902] Alan Kirman and Miriam Teschl, 'Searching for Identity in the Capability Space' (2006) 13 Journal of Economic Methodology 299.

mapping out the possibilities. As I show, for the following reasons, the first and second suggestions may not be feasible.

As regards the first suggestion of implementation, access to health records that document the means of conception may be granted upon request when attaining the age of majority. However, even if there was a legal right to access such a record, the right cannot be properly exercised unless the children are aware that there is something to know. In other words, the right can only be exercised when the relevant children are first told by their parents that they have been genetically modified prior to birth. Ironically, the official record stating the means of conception is rendered pointless when the children already know the means of conception from their own parents. Next, a right to know may also be implemented by giving an original birth certificate upon birth with the status of conception. As observed in the donor-conception debate, this suggestion may be subject to criticism for being discriminatory towards the children born via HGE by labelling them as a distinguished group upon birth. This leaves us with the third suggestion, which is arguably more feasible but raises both pros and cons in its implementation.

Regarding the third suggestion, a right to know may be implemented by promoting a moral duty on the parents to tell, perhaps with state encouragement. For instance, there should be an obligation imposed on the clinic to advise the parents to tell; and to educate the parents about the importance and benefits of telling (or possible harms of not telling). Relying on the current legislation on assisted reproduction, it is likely that this suggestion may be extended to the children born via HGE. Despite being the most feasible solution, it may not be the best solution from the child's perspective. Leaving the decision to parents as to whether or not to inform the child of the fact of conception means that parents may keep the truth a secret.[903] Thus, leaving parents to decide whether to disclose the means of conception to the child when HGE is adopted, though respecting parental autonomy in the reproduction and a right to respect for family privacy, may *not* effectively protect the resulting children (as assessed from a child-centred approach and through a capability approach). This is in line with Frith's position, albeit in the donor-conceived context,

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[903] F Shenfield and SJ Steele, 'What are the Effects of Anonymity and Secrecy on the Welfare of the Child in Gamete Donation?' (1997) 12 Human Reproduction 392. The authors argue, in the context of gamete donation, that the parents should be allowed to decide in their own judgment of what is "right" for their children.

that placing the duty of disclosure on parents' shoulders signifies greater weight being given to parents' rights instead of the child's, even though the right to know is discussed as a right of children.[904] Frith further warns that a parent-directed approach may reinforce the tendency towards secrecy.[905] Secrecy has been argued as having the implication of undermining trust in family relationships.[906]

One may respond that this leaving-to-parents is arguably in line with the complex nature of family relationships and the notion that family dynamics vary from one another even in a single community or society.[907] It has been argued that the decision not to disclose gamete donation may be influenced by social and cultural factors, and in fact with an intention to protect the child from harm, e.g. the potential social stigma.[908] Thus, disclosure of truth may not always be beneficial to children from the parents' point of view. Although merely speculative at the moment, I highlighted earlier that the societal attitude towards HGE may similarly have a great influence on how the resulting children see themselves since narrative identity is relational. As discussed in Part I, the position that ascertainment of truth may not always be beneficial to the child has also been recognised by the UK courts in the language of best interests of the child. Hence, non-disclosure may, in some cases, be deemed to better serve the interest of the child. Nonetheless, as Cowden argues, 'a harmless action may yet still constitute a foul'.[909] Cowden, in the context of gamete donation, highlights that truth-telling is a respectful practice with an impact on the (narrative) identity of the individual, and this claim becomes stronger especially when the government is involved in the process (say, legitimising the procedure in reproductive setting); hence, there should be measures in place to safeguard disclosure to the resultant children so as not to be part of the deception.[910] Following

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[904] Supra note 762, Frith (2001) 478.

[905] Ibid.

[906] Supra note 643, Daniels and Taylor (1993).

[907] Stephen Gilmore and Lisa Glennon, *Hayes and Williams' Family Law* (5th edn, Oxford University Press 2016) 361.

[908] Patricia Hershberger, Susan C Klock and Randall B Barnes, 'Disclosure Decisions among Pregnant Women who Received Donor Oocytes: A Phenomenological Study' (2007) 87 Fertility and Sterility.

[909] Supra note 390, Cowden (2016) 107.

[910] Ibid, 104-105

this reasoning, it is arguable that if the government decides to legalise HGE in the clinical setting, it should also actively encourage parents or clinics to disclose the truth of conception or take direct steps to inform the resultant individuals. In line with the capability approach which takes into account external factors in the practical implementation of a certain right, one way to encourage parental disclosure may be by imposing a wider obligation on the government to encourage an open-minded society (one which is envisaged by the Court of Appeal in the transgender case discussed earlier) and to monitor, identify and reduce the stigma (if any) associated with the technology. Such action may reduce the fear of stigmatisation which could be one of the factors parents choose not to disclose the fact of employing genome modification (and thereby affecting the exercise of children's right to know). This line of thinking is necessary to better safeguard the narrative identity of the resultant children (in a way that is positive to the individual's sense of self instead of bringing negative impacts on his/her sense of self) which in turn affects many other aspects of the well-being of the individual.

Despite all these concerns, it is undoubtedly a step forward if the claim of a right to know for the prospective children can be first successfully established and recognised in the context of HGE. As I have argued throughout this chapter, there is a strong conceptual basis to ground such a right, particularly on a narrative-based account of identity, supplemented by the capability approach. This line of argument is also consistent with the multi-faceted concept of identity I discussed in Chapter 5, given that narrative identity is only one aspect of the whole identity which, as I have argued here, should be given more ethical weight in the context of HGE.

6.7 Conclusion: Summary

Part I of this chapter highlighted that there is a legal and conceptual basis for a right to know based on (narrative) identity interests. From an international perspective, children's right to information has been recognised as part of European human rights and via the international children's right convention (albeit not directly protected in the latter). In the UK, a right to know (genetic parents) has also been legally recognised on several occasions, including in the context of adoption, gamete donation and paternity proceedings. In general, children's right to information about their past or their origins is recognised as protecting a vital interest to their construction of identity.

Drawing upon the discussion in Part I, I argued in Part II that there should be a right to know the mode of conception for the prospective children born via HGE. Such a claim for a right to know does not commit to a genetic determinism or essentialism view because it is based on narrative identity which is dynamic and relational. I argued that knowing one has been genetically modified before birth is pertinent for the resultant child in forming his/her self-conception and to understand his/her own identity (especially when HGE is always likely to have unpredictable effects, even when it is permitted for reproductive use). Furthermore, closely related to the previous point, if one's self-narrative were formed due to false information, one may develop a distorted identity. Having a coherent and genuine identity deserves ethical and legal consideration as it is a central capability that affects the evolving capabilities of children, including their capability to autonomy. Accurate and truthful information helps children make informed decisions in life, including whether or not to participate in the long-term monitoring mechanism and their future reproductive decisions. These decisions in turn also affects how they construct their identity. Thus, I stressed that this right to know the mode of conception should be given more attention in the ethico-legal debate on HGE.

If the right to know can be established, then it is also important to consider whether the rights can be guaranteed in practice. Based on the capability approach, whether or not the right to know can be actualised first depends on whether the children have the basic capabilities to exercise it; and second, it also depends on the societal, legal and political structure – whether there is practical enforcement in place to actualise the right in reality. As I argued, the most feasible implementation plan (though it may not be the best solution from a child-centred point of view) is an active encouragement by the government on the clinics to advise and educate parents about the need and benefits of telling children the fact of being born genetically modified together with active steps taken by the government to reduce potential social stigma related to the use of HGE.

Chapter 7 – Concluding Chapter

In this final chapter, I provide a review of the overall arguments alongside the original contributions of this thesis. I also consider some possible concerns that might be arisen from my arguments. At the end of the chapter, I delineate further questions or areas that are worth further research.

7.1 Review of Arguments, Contributions and Some Further Thoughts

With the advance of science and technology – from human heritable genome editing ("HGE") taken as mostly theoretical due to substantial technical risks and uncertainties several decades ago[911] to the recent CRISPR genome-edited twin babies born in China[912] – a substantial question in the HGE debate that urges for attention is certainly no longer whether one can offer such technology in human reproduction, but rather if one *should*. My primary aim for this thesis was to investigate the ethical and legal questions related to the reproductive use of HGE from a children's perspective. Hence, this thesis advocates paying more attention to the consequences for the resulting children who are the actual subjects of HGE before embarking on the parental right to resort to this technology within the realm of reproductive freedom. Undeniably, parental perspectives are indeed important in the debate of HGE especially when unreasonable curtailments of parental reproductive rights may be linked with part of the notorious historical lesson of the eugenic movement (see Chapter 2). However, it is significant to note, as I pointed out in Chapter 2, that laws (and the courts) are often ready to intervene in parental decisions in cases where there is substantial harm or risk of harm to the children as a result of those decisions. The potential clinical use of HGE bears a substantial risk of harm given that it is hard to predict the gene's interaction after modification and that any effects from it will be inherited to the children's descendants. Thus, this thesis presumes that even if the use of HGE can validly fall within the protection of reproductive freedom, there can be some restrictions justifiably imposed on how it should be used. Taking a child-centred approach, this thesis has made original contributions to the HGE debate through the incorporation of a capability approach and a multi-faceted

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[911] See e.g. supra note 1, President's Commission (1982) 46-47.

[912] See Chapter 1 for more discussion on scientist He Jiankui's affair.

understanding of “identity” as well as the further emphasis on the interactions between capabilities and “identity”.

I have emphasised a need to rethink what we mean by “hearing children’s voices” in the context of HGE given that “protecting children’s interests” or “to prevent children from contracting genetically caused diseases” can be empty rhetoric and easily be exploited, as depicted from scientist He’s affair (see Chapter 1), in a way to obscure the risks imposed by this technology (e.g. the possible side effects due to the alteration of genes) or to mask others’ interests (e.g. financial interest of the researchers/private corporations). However, getting children’s interests attended is not always straightforward, especially when it comes to preconception cases where they concern the welfare of *future* individuals, rather than existing ones. There is a deeper philosophical issue when we evaluate the possible impact of technologies such as HGE on future offspring considering that the technology or the decision to use that particular technology that causes the child’s being born in a certain condition is also the necessary condition of the child’s being born in the first place. This is the non-identity problem as I discussed in Chapter 3. There, I showed that the *applicability* of the non-identity problem is itself debatable in the context of HGE. The discussion of non-identity not only flags to us difficult questions about “identity” in the case of HGE (further discussed below), but more importantly, it also leads us to consider ways around the non-identity problem (assuming that it does apply in the case of HGE) so as to make sure that future children do not fall outside the ambit of ethical consideration in regard to the clinical application of HGE.

Apart from the non-identity considerations, another commonly raised argument in the HGE debate is the notion of “open future”. As I argued in Chapter 3, the conceptual and practical ambiguities associated with Feinberg’s open future principle render it inadequate to be a guiding principle in assessing the ethical acceptability of certain use of HGE. In addition to this, another issue with the open future principle which makes it fall short of appropriately consider and safeguard children’s interests is that it regards the child as merely becoming a future adult thus failing to recognise the interests of the child as being a child. I have argued for a shift from focusing on a range of opportunities or choices to be chosen from when they grow up to the emphasis of developing basic capabilities during childhood as well as adulthood which can further lead to more capabilities and thus opportunities.

As shown in Chapter 4, the capability approach is able to capture both the former and latter, unlike the open future principle which focuses on the former. The incorporation of a capability approach in considering the ethical acceptability of HGE therefore, I think, asks a clearer and more fitting question with future children properly considered: whether the child will be born having the basic capabilities with or without the use of HGE. This view is in line with my argument for a well-being threshold principle as a response to the non-identity problem (see Chapter 3, section 3.1.1 and Chapter 4, section 4.2.1) in which children can be harmed if their well-being falls below a certain threshold (more specifically, a threshold of basic capabilities) even if it is the only way they could have existed.

In Chapter 4, I have argued that the capability approach has a further role in shedding light on what could constitute these “basic capabilities” and why such capabilities should be given special ethical attention. Along with the observation on how there is already a step away from the conservative attitude towards HGE (for instance, in the most recent report by the National Academy of Sciences, it is suggested that HGE should only be used for severe monogenic genetic diseases, see Chapters 1 and 4), a capability view of “health” provides the conceptual basis currently lacking for the proposed health-related use of HGE in that it explains how health capabilities (the abilities to be healthy) can be both fertile functioning and corrosive disadvantage and therefore one of the central capabilities that deserves special ethical significance. This thinking helps us to understand, from a philosophical grounded view, why the use of HGE may be ethically more acceptable in the case of prevention of genetic diseases as compared to enhancement purposes.

Furthermore, I have utilised and refined Ruger’s notion of central health capabilities for new insights in policymaking in relation to the eligibility for the clinical use of HGE. I have argued that whilst health capabilities generally deserve ethical attention for they facilitate many other capabilities, only those diseases/conditions that affect central health capabilities (I categorise early onset diseases that cause cognitive or mental impairment as those that would impact central health capabilities) ought to fall under the ethical permissible use of HGE. There might be concerns that such criteria for the permissible use of HGE are too restrictive. As a response to this, I share the sentiment of Devereaux that HGE is ‘a unique category of modification’ because ‘early-stage research cannot guarantee protection against unknown, particularly long-term, health consequences' and 'it is one that is irreversible and extends beyond the individual and the children of the individual'.[913] Apart from children's perspective, the use of HGE may also have non-negligible implications on human evolution[914] and as indicated in Chapter 2, may give rise to market-based eugenics. While this thesis does not discuss in detail the wider societal implications from the potential application of HGE in reproduction, these reasons, combined with the considerations of future children, constitute valid grounds that render a restrictive use of HGE justifiable. I thus maintain that this restrictive suggested use of HGE in this thesis is reasonable and should remain before and until concerns about HGE's future biological consequences and other socio-ethical implications are properly addressed. Of particular relevance and noteworthy is of course the concerns from a genetic disability perspective. As Petersen argues, the development and assessment of new technologies including genome editing should include the *lived realities* of genetic disability.[915] Though the notion of the central health capabilities in this thesis is argued from an objective point of view, it might be challenged in terms of whether such notion could or should be expanded to include more genetic conditions and more importantly, how this decision should be made, given that the technologies and genomic knowledge transform gradually. In respect of this concern, more empirically informed insights from people living with genetic disabilities should be advanced to further test and enhance my proposal here as regards the appropriate clinical targets of HGE.

The well-being threshold principle coupled with the redefined notion of central health capabilities in this thesis may have ramifications for other reproductive decisions, particularly in terms of the so-called 'procreative responsibility' that considers the question 'under what conditions is it morally responsible to procreate with the intention of parenting'? [916] This thesis has focused on the question of what

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[913] Supra note 592, Brothers, Devereaux and Sade (2019) 6-7.

[914] Jim Kozubek, 'How Gene Editing Could Ruin Human Evolution' (Time, 09 January 2017) <https://time.com/4626571/crispr-gene-modification-evolution/> accessed 30 August 2021.

[915] Alan Petersen, 'The Best Experts: The Narratives of Those Who Have A Genetic Condition' (2006) 63 Social Science & Medicine 32; also see Felicity Boardman, 'Human Genome Editing and the Identity Politics of Genetic Disability' (2020) 11 Journal of Community Genetics 125.

[916] David DeGrazia, 'Procreative Responsibility in View of What Parents Owe Their Children' in Leslie Francis (ed), *The Oxford Handbook of Reproductive Ethics* (Oxford University Press 2017).

way HGE ought to be used from a children's viewpoint, but it has not directly dealt with the question in regard to the parental obligation in procreation and more specifically, in the case of HGE. The latter question depends on other considerations such as whether there is an obligation to have a healthy child (one with the basic capabilities, or in particular central health capabilities) and whether there might be an obligation to use HGE or obligation not to have a child (if the parents refuse to resort to HGE where it will be the only alternative to have a healthy child)? At first sight, my arguments in this thesis might have implied affirmative (yet controversial) answers to these questions. This may further lead to a possible expansion of wrongful life suits. These questions cannot be properly addressed by merely resorting to children's interests. What is necessary for further examination is also a more detailed and balanced account of parental rights and obligations.

Apart from the capability approach, the concept of "identity" is also of significance in the case of HGE. How much changes made on the genes or genomes would constitute a change to "identity" and how would an identity-change bring ethico-legal implications are questions that cannot be neglected in the related policy and regulations. However, as I explained in Chapter 3, the existing discussion has been scattered with different interpretations of "identity" in approaching these questions (e.g. some focusing on the non-identity cases which have its focus on numerical identity; the international regulations of HGE seems to prohibit the introduction of modified genes to the descendants and imply a possible right to a genuine "genetic identity"). I do not deny that these discussions are important in the debate of HGE but what is needed is also an inclusive discussion on distinct concepts of "identity" as well as, I emphasise, an understanding of their possible interactions with one another in the context of HGE. This observation has provided a space for a novel contribution from this thesis, that is to provide a comprehensive conceptual and normative analysis on different concepts of "identity", hence clearing the existing confusion caused by a lack of understanding of the possible, various interpretations of "identity". I have argued that, by understanding a multi-faceted account of "identity" which emphasises not only that "identity" connotes different interpretations in the context of HGE but also that they are interrelated, there need not be a definite answer to the "identity-related" questions from the choice of a single concept of identity. I have demonstrated that the international regulations of HGE which prohibit the introduction of modified genes do not give rise to a right to an untampered “genetic identity” in its literal sense and that the international conventions seem to be protecting human species identity. Hence, the ultimate concern that might render HGE not ethically acceptable is arguably those changes made on the genes or genomes prior to birth that would constitute a change in human identity as a species (see section 7.2.3 below). Assuming now that the use of HGE will not change the “human identity” as a species, we can then proceed with the questions stated at the start of this paragraph by taking into account other kinds of “identity”. I have introduced different types of “identity” in Chapter 5 which I think are the most relevant to the debate of HGE, that are genetic identity, numerical identity, qualitative identity and narrative identity. There, I have also argued that while these identities are interconnected – e.g. a change in genetic identity might change the numerical, qualitative and even narrative identity of an individual; a change of qualitative identity will also change one’s numerical identity depending on which accounts of persistence one adopts – narrative identity should be given more ethical attention in the policy of HGE, especially when we are taking a child-centred approach. Therefore, in addition to clearing the confusion in the overall HGE debate, an identity-based discussion particularly through recognising an identity-related interest (as I argued in Chapter 6) can be a route to better safeguard the resulting children born via HGE.

In Chapter 6, I have argued that being able to develop own identity is a central capability for it helps individuals realise other capabilities such as the capability to autonomy. Having necessary information such as the fact of being born genetically modified may contribute to one’s identity formation, particularly to make sense of what has happened or might happen to his/her physical health and to understand the requirement or perhaps encouragement to participate in the long-term monitoring programme as well as to make informed choices regarding their future health and reproductive plans. This narrative-based identity interest should be protected by a right to know which would ensure disclosure of this piece of information to the resultant children. No doubt that how we present certain information will somehow influence how one reacts or responses to that piece of information. For instance, in the debate of gamete donation, Leighton describes it as a harm when she observes how the claim for a right to know genetic parents in that context may have upheld the hetero bionormative presumption that ‘good families must be genetically related’, thus ‘is linked to the claim that family-making *should* be done through biogenetic reproduction (emphasis added)'.[917] Hence, in the context of HGE, concerns might arise to such claim in that by emphasising the need to provide a certain piece of information, there is an indication that we find that information significant, and perhaps by implication, what the affected individuals ought to find significant (which in turn shape their identity formation).[918] I wish to briefly address this concern here.

First, as I pointed out in Chapter 6, defending a right to know the mode of conception is only worth defending if such information 'has the potential to make an important, even fundamental difference in one's life'.[919] A narrative-based account of identity highlights how such information can 'help us to develop self-narrative that are resilient and intelligible in the face of embodied experiences'.[920] Second, the possible normative impacts from certain information should not influence the possible positive value of the information (or in other words, it should not make the claim for the information less desirable). For instance, in the field of epigenetics, there have been arguments that epigenetics risk messaging may presume maternal responsibility which may unreasonably influence the allocation of responsibility ascribed to the women.[921] These observations however do not justify researchers not conveying the significance of this piece of information that might bring impactful change to people's lives; instead they do justify the claim that researchers should convey epigenetics message responsibly.[922]

Last and perhaps more importantly is the fact that genetic information has already been shaping identity nowadays, hence getting to know one's "origins" although is a novel claim in the context of HGE, is not novel in popular culture. As McGuinness, Koops and Asscher conclude, even with the claim that 'genetic information is

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[917] Supra note 204, Leighton (2013) 54

[918] My thanks to the two examiners for flagging this important issue.

[919] Supra note 857, Ravitsky (2014).

[920] Supra note 673, Postan (2017) 267

[921] Sarah S Richardson, Cynthia R Daniels, Matthew W Gillman and Others, 'Don't Blame the Mothers' (2014) 512 Nature 131; also Kristen Hessler, K, 'Epigenetic Inheritance and the Moral Responsibilities of Mothers' (2013) 15 AMA Journal of Ethics 767.

[922] Ibid, Richardson and Others (2014).

important but not special … there is no escaping the deeply ingrained notion that genes are special'.[923] Thus, it is hard to deny the complex relationship between information and identity formation especially in the genetics context and which merits our attention.[924] Consequently, in the case of HGE, the concern regarding how the claim for a right to know the mode of conception might *indirectly influence* how one should develop their identity, I think, does not reduce the ethical weight of a claim to a right to know for the resultant children. Rather, more attention should be given to how we can present information in an identity-support manner. Considering the dynamic nature of narrative identity (in that everyone may respond differently to it) as well as the complex nature of family matter, I have argued in Chapter 6 that a more feasible approach to implement a right to know that can respect parents' rights in line with safeguarding children's interests is by way of government's guidelines (in the form of policies or professional guidelines) which are usually more flexible and context-based. In terms of how we can provide certain piece of information in a supportive way, two guiding principles suggested by Postan are worth mentioning here: first,

> 'A discloser should not seek to tell the recipient what roles the personal bioinformation in question ought (not) to occupy in her self-conception or foreclose the kind of story she wishes to construct, but support her own (re)construction of her self-narrative in light of the information and what it tells her about her health, body and biological relationships'

and second,

> 'The process should be discursive and collaborative in a way that permits the discloser to appreciate the particularities of the recipient's perspective and vulnerabilities, while also providing the recipient the tools and space to work out what the bioinformation means for her life and identity'.[925]

Both of these principles have taken into account the dynamic nature of narrative identity and the possibility that information can both empower and harm the

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[923] Supra note 646, McGuinness, Koops and Asscher (2010).

[924] Ibid.

[925] Supra note 673, Postan (2017) 256.

receiving individuals in their construction of identity. How these principles can be implemented into the context of HGE is worthy for further examination.

7.2 Summary of Areas for Further Research

7.2.1 Balancing children's interests with parents'

One major concern with a child-centric approach is that it may impinge on parental reproductive rights and choices in the use of HGE. In Chapter 2, I briefly explored the parental reproductive freedom and argued that this right should not be seen as absolute. Hence, it is likely that at times of conflict, children's interests can be a reasonable ground to justify interference on parental reproductive freedom. This area deserves further research specifically as to the possibility of *reconciling* the conflicts between children's interests and parental rights in the context of HGE. Considering that the door may one day be open for HGE to be used for certain genetic diseases, it is also worth considering whether there could or should be a moral obligation on parents to avoid certain forms of reproduction,[926] in line with a child-centred approach in the context of HGE. Furthermore, the issue on how to strike a balance between the proposed right to know for the resulting children and parents' right in this matter also presents an area worthy of further examination.

7.2.2 The possibility of the expansion of tort law

As this thesis argued that children should be born with basic capabilities (see Chapters 3 and 4), there arises a question as to whether this would give rise to a wrongful life claim. Currently, it is unlikely that the claim can succeed in the UK.[927] This thesis has not discussed the plausibility of the claim of wrongful life and its applicability in the context of HGE.[928] Thus, it is an area worth further examination. Not only that, but it is also suggested that the resultant individuals should be entitled to compensation for losses caused by direct and significant intervention in his/her

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[926] Supra note 428, Purdy (2010).

[927] For a discussion on the wrongful life claim in the UK, see Chapter 3 (section 3.1.1) of this thesis.

[928] Shawna Benston, 'Yesterday's Child, Tomorrow's Plaintiff: Why We Should Expect an Uptick in Wrongful-Life Suits Following Embryonic Application of Gene-Editing Technologies' (2019) 19 The American Journal of Bioethics 41.

genome since there is a lack of total ban by the law on genome editing.[929] Hence, it is worth examining the civil liability for damages from editing the genome of human gametes or human early embryos. Furthermore, if it is accepted that (narrative) identity detriment can bring adverse effects to the resulting individuals as this thesis pointed out in Chapter 6, it is then also worth researching further the wider impacts of the proposed right to know for the prospective children born via HGE, including whether negligence claims should be expanded to recognise the identity-related detriment as a form of harm under tort law.

7.2.3 Deciphering "human" in the debate of heritable genome editing

While this thesis has constantly pointed out that HGE may be ethically impermissible when its use would alter the whole human identity or species identity, it has not provided an analysis on what amounts to "human", what is needed to protect this "humanity", what "human nature" should be retained in the context of HGE and first of all, should "human nature" or "humanness" be given a fundamental intrinsic value so as to protect us from the technological manipulation of our genome?[930] These questions are urgent and essential for a thorough examination, especially to answer whether human enhancement should or could be allowed in the context of HGE and whether this would affect the suggested use of HGE for health-related purposes.

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[929] Supra note 470, Krekora-Zajac (2020) 3.

[930] See for instance, Kurt Bayertz, 'Human Nature: How Normative Might It Be?' (2003) 28 Journal of Medicine and Philosophy 131; Antonella Corradini, 'On the Normativity of Human Nature: Some Epistemological Remarks' (2003) 28 Journal of Medicine and Philosophy 239.

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