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Reinterpreting "Genetic Identity" in the Regulatory and Ethical Context of Heritable Genome Editing

Abstract

Heritable genome editing (HGE) involves germline modification, which is prohibited by several international conventions in order to protect "genetic identity". This article provides a conceptual analysis of the concept of "genetic identity" and offers normative reflections as to how it should be interpreted in the context of HGE. Particularly, this article examines the purported right to retain "genetic identity" and the right-to-know "genetic identity" to explore the possible implications of these understandings on the debate concerning HGE on nuclear genome. The arguments of this article are twofold. Firstly, it argues that a right to retain "genetic identity", that is a right to have untampered genome, is unlikely to be plausibly established following the current international provisions as a ground to determine the ethical acceptability of HGE. The article points out that the intention behind the international provisions to "protect the human genome" is to protect human (species) identity. Secondly, it argues that the right-to-know "genetic identity" based on a narrative-based understanding of identity should be given more weight in the context of HGE because it better safeguards the interests of the children born via the technology, should the technology be legalized for clinical use.

Keywords: *heritable genome editing, genetic identity, children*

Introduction

Human heritable genome editing (HGE) involves germline modification where modifications are made on the germ cells (sperms or eggs) or early human embryos. In contrast to somatic genome editing (that is modification of genes of a particular, existing patient), the technique has wider-reaching consequences that extend far beyond the individual to impact upon future generations. It is partly for this reason that HGE is regarded as far less ethically acceptable than somatic genome editing (NCB 2016a), and why its use for human reproduction is currently subject to an international prohibition (Araki and Ishii 2014). Although the acceptable safety level for its clinical use has yet to be reached, the introduction of CRISPR-Cas9 (see, e.g., NCB [2016b] for a summary on

CRISPR-Cas9) signifies that there is now a tool which is able to target and edit genes more efficiently with high precision; the simplicity of the technique also leads to fairly low cost (Berkeley News, July 23, 2015). Such developments therefore demand a more detailed regulatory framework (Turkmendag and Murphy 2019) that can accommodate and address the broader ethical concerns. This demand has even greater urgency following the news that the world's first genetically modified twins have been created by Chinese scientist He Jiankui[1] amid the international prohibition on HGE (The Guardian, November 26, 2018). Despite the ongoing controversy on HGE, there seems to be a shift of attitude towards the overall acceptance of the technology, especially when it is positioned within a "therapeutic"[2] path. For instance, acknowledging that there are still gaps in the overall safety of HGE, the recent report by National Academy of Sciences (NAS 2020, 1 & 3) suggests that HGE could constitute "an important option for prospective parents with a known risk of transmitting a genetic disease to have a genetically-related child without that disease" and recommends, inter alia, that if HGE were to be introduced into clinical settings, it should be "limited to serious monogenic diseases". In the UK, it is "within a framing of reproductive choice and disease prevention" that the mitochondrial replacement technique ("MRT")[3] has been extensively debated and eventually introduced into clinics for women with mitochondrial disease who want a genetically related, healthy child (Dimond and Stephens 2018, 5). Therefore, legalization of new technologies, including HGE, may distant itself from the wider ethico-legal debates. Nonetheless, there is a need to revisit the fundamental concepts that have informed our legal thinking on this issue.

Noting the variety of meanings associated with the concept of "genetic identity" (Goekoop et al. 2020) but yet a lack of detailed analysis as to what it means and how it should be understood in the context of HGE, this article thus takes up two tasks. First, it provides a conceptual analysis of "genetic identity" with a focus on the international and UK perspectives. Second, it offers normative insights into the existing debate of HGE as regards to the interpretations of "genetic identity", drawing upon the literature on law, bioethics and social science. Unpacking the concept is essential, particularly in light of prior experience in the UK regulation of related technologies, for instance, MRT, which has shown that "genetic identity" can be easily manipulated to serve the ends of different interest groups. In this article, we map the conceptualization of "genetic identity" into two questions commonly raised in the HGE debate: (1) whether and to what extent HGE should be ethically allowed (see, e.g., Gyngell, Douglas & Savulescu 2017); and (2) if we agree that HGE is ethically acceptable, how should it be introduced to the clinical settings in a responsible way? (see, e.g., Cwik 2020). In regard to (1), we examine a purported right to *retain* "genetic identity"; while for (2), we explore a right-to-know "genetic identity". The arguments made in this article are twofold. Firstly, we argue that the "genetic identity" which the international provisions seek to protect in the context of genome editing does not connote having a right to retain a genuine "genetic identity" (an untampered genome) but rather, a protection of human (species) identity which need not involve a total ban on modifying the human genome. We therefore recommend focus to be shifted to questions such as what protection of human (species) identity should entail in the context of HGE and how this could further govern the ethically acceptability of HGE. Secondly, in respect of a responsible translational pathway for HGE, we argue that a narrative-based understanding of (genetic) identity in light of a right-to-know should be given more emphasis by the relevant policymakers as a safeguard for the prospective children born via the procedure.

1. A Right to Retain "Genetic Identity"

We begin by exploring one of the key interests which underpins the current prohibition in international law of germline modification: the protection of "genetic identity" (Boussard 2009). This section focuses on how "genetic identity" is interpreted in the international provisions by analyzing the claim for a right to retain "genetic identity" since the latter has been frequently raised in the academic literature as an opposing argument against the use of HGE (Nolan 1991, 614; Holtug 1998; Baylis 2013, 534). This analysis is needed because there is currently a lack of detailed examination of such a notion and the plausibility to rely on such a claim to justify the legality and ethicality of HGE thus remains vague.

This notion arguably stemmed from the recommendation made by the Parliamentary Assembly of the Council of Europe ("PACE") in 1982 where, in relation to genetic engineering, the PACE recommended that there might be a "right to inherit a genetic pattern which has not been artificially changed". Article 13 of the 1997 Convention on Human Rights and Biomedicine ("Oviedo Convention") – the first legally binding international instrument to highlight the collective interests of human beings in the context of biomedical innovations – also provides that "(a)n intervention seeking to modify the human genome may only be undertaken (…) if its aim is not to introduce any modification in the genome of any descendants". On its literal interpretation, *any* form of HGE is thus prohibited because the modified effects would, in fact, be passed on to descendants. The claim for a right to retain a *genuine* "genetic identity", where "genuine" means without any intentional interference, hence connotes the idea that 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 (Parens 1995, 175).

The right to retain a genuine genetic identity appears to be based on two possible grounds: (1) 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 UNESCO's Universal Declaration on the Human Genome and Human Rights 1997 (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*".

1.1 Human genome as the "common heritage of humanity"

Reading the Article by itself, it is unclear what it means to view human genome as a common heritage of humanity. Referring to Agius' work (1998, 75), 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. This genetic heritage belongs to all human beings and it goes beyond "national or temporal boundaries" and is "the biological heritage of the entire human species" (Agius 1998, 76). Nonetheless, the applicability of the common heritage view to human genomes is disputable: it has been suggested that there is no "germline" in human species in the genealogical sense (Juengst 1998, 87)[4] and that it is hard to identify one single "thing" as the human genome due to "genetic variations" in which every individual owns a different set of genes (Resnik 2005, 200).

Even if we set aside the scientific viewpoint, applying the concept of common heritage to human genome, particularly to the context of HGE, creates other doubts. 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 (Primc 2020, 42). 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 (Buxton 2004, 692). Hence, it is not entirely clear if this principle can be applied to the legality or ethical acceptability of germline editing. Primc (2020, 43) observes that the common heritage idea does not provide an answer to the ethical permissibility of germline modification, if it is interpreted as giving the people or nations equal property interests in a territory or resource (Ossorio 2007, 427-428). In a similar vein, Hey (2014, 264) opines that the common heritage of humankind which aims to serve human interests may be fit to address "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 be "human" in a collective sense. 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 (2007, 430) 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". Primc (2020, 44) 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. This duty, if understood with the right to an unaltered genome, may stipulate that there should be no intervention on the human genome by any technical concerns (Primc 2020, 44). Unfortunately, further problems remain with the "duty to preserve human genome".

Firstly, the idea of "protection of human genome" is problematic as it connotes genetic determinism[5] – an idea which has consistently been rejected by the Legal Commission of the International Bioethics Committee of UNESCO ("the Committee") (Division of the Ethics of Science and Technology 1999, 3, 62, 68, 75), leading to an eventual inclusion of a provision to condemn the notion of genetic determinism in the 1997 Declaration (Article 3). In the preparatory work of the 1997 Declaration, it is also emphasised that a right to respect one's genetic heritage (that is not to be discriminated against) should not be seen as equivalent to the sanctity or inviolability of human genome (Division of the Ethics of Science and Technology 1999, 71). 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" and that "the purpose of protecting the human genome is to safeguard the integrity of the human species" (Division of the Ethics of Science and Technology 1999, 62). 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).

Secondly, if the duty to preserve the human genome is based on safety concerns, arguably then a right to a genuine genetic identity is only a provisional right because it can only sustain until the safety concern is resolved (Primc 2020, 44). The Committee clearly stated that the prohibition on germline editing at the time of drafting the 1997 Declaration is due to the state of scientific knowledge at that time (Division of the Ethics of Science and Technology 1999, 62). This is also demonstrated in the Oviedo Convention which allows amendment of the provisions (see Article 32). Consequently, a right to non-modified genomes is at best temporary and can be lifted when the technology is proven safe and effective enough. Clearly, the support in favour of this right is not as strong as first claimed in 1982, leaving such a duty to preserve the human genome vague or even redundant. It is notable that even when the PACE 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.

Hence, even if it is agreed that human genome is a common heritage, it is questionable whether this view would constitute a right to retain a genuine genetic identity. One possible remedy for this situation is to adopt what Resnik (2005) has suggested, albeit in a patenting human genome context, that there should be a symbolic interpretation (instead of literal interpretation) of the common heritage. UNESCO itself has stressed this symbolic sense in the first Article. Looking at the preparatory work, it may be emphasized that the purpose of including the idea that 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" (Division of the Ethics of Science and Technology 1999, 3). Therefore, it can be concluded that genome editing, including HGE warrants high precaution from us regarding its clinical implementation and must be examined on its own merits to determine its legality and morality.

1.2 Human genome and human dignity

Another possible view to defend a right to a genuine genetic identity is through the concept of human dignity. Article 24 of the 1997 Declaration indicates that HGE 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 (2020, 3) points out that the position implied by Article 24 is different from Article 11 which clearly forbids reproductive cloning on the ground that it *is* contrary to human dignity. Hence, it is argued that the wording of the 1997 Declaration suggests that certain form of genetic intervention before birth may be acceptable and need not be a threat to human dignity or humanity (Krekora-Zajac 2020, 3).

How the concept of human dignity 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. This indicates that there is "an unconditional worth that everyone possesses by virtue of being human" deserving respect (Andorno 2011; Fukuyama 2002). 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 a counter-intuition that those born as a result of such technique are somehow less "dignified" (or afforded less dignity) than those who are not. Nonetheless, the concept of human dignity continues to gain traction in the HGE debate. In the updated statement by UNESCO concerning genome editing in 2015, it is stated that HGE would "jeopardise the inherent and therefore equal dignity of all human beings". This statement seems to go against what is understood above which says that every human being, including those born genetically modified before birth, should be treated as having the same dignity as any other human being.

We argue that one possible interpretation of "human dignity" which is more plausible may be that HGE should only be carried out (if proven safe and effective) in a way that does not involve instrumentalization of the resultant individuals (van Assche and Sterckx 2014, 278). Andorno (2009, 228) 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. Scientist He Jiankui's experiment is, regrettably, a good illustration of such instrumentalization. Scientist He and his team seem to have discounted the interests of the resultant children (and the prospective parents) to their own interests. In their hope for a breakthrough in the field of HGE with fame and profit (Greely 2019, 142), they disregarded the primacy of interests and welfare of resulting individuals born via the premature procedure over the sole interest of science. It is thus arguable that they fail to demonstrate respect for human dignity in such instance. "Human dignity" if interpreted in this way seems to have a more substantive place in the current context of HGE. Still, there seems no case for a right to a genuine genetic identity.

1.3 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. Looking at the preparatory and drafting process of the 1997 Declaration, it is 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 (see Division of the Ethics of Science and Technology 1999, 118, 122, 126, 131) (notwithstanding that the phrase was substituted with "human family" in the final version).[6] The intention to protect the human species is also acknowledged in the preparatory work on the Oviedo Convention: the Working Party noted that the term "identity" of the human being covers both "membership of the human species (so ruling out hybrids) and the individual's genetic identity" (Steering Committee on Bioethics 2000, 10). 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 intention behind the protection of this "genetic identity" arguably stems from the fear that modification will cause unforeseeable mutations to the genome or bring about a change in human nature itself (Marks 2002, 115; CoE 1997, para 89). Preserving humanity, in this context, may be interpreted as preserving the identity and integrity of human beings against certain biotechnological advances (Andorno 2011, 57).

The above discussion suggests that it is unlikely that a legitimate claim for a right to a genuine genetic identity can be established. It is neither scientifically plausible, nor can adequate justification be found in the current international instrument. Hence, we argue that a right to retain a genetic identity is not adequate to provide a solid ground to answer the ethical acceptability of HGE. Although there is a general global consensus in favour of a ban on the clinical use of HGE, with an emphasis on the protecting the identity and integrity of human beings, it seems to us that none of the international documents offer useful guidance on this issue. The advances of science demand a precise meaning and consideration of the impact of prohibiting HGE (Montgomery 2018); or at least a closer consideration of what it means to preserve humanity. We suggest, in line with Montgomery's (2018) recommendation, to re-examine the current ban under Article 13 of the Oviedo Convention, that the international framework may be more nuanced and better regulate HGE if it directly engages with the question of what it means to be a human, and whether humans have a genetic identity that needs to be protected as a part of human heritage. These questions should therefore be included in the ongoing ethical and regulatory debate on HGE.

2. A Right-to-know "Genetic Identity"

In this section, we examine another conceptualization of "genetic identity". This understanding answers the questions of how responsible translational pathways of HGE can be, should the technique be introduced to the reproductive setting. Particularly, we explore a right-to-know one's genetic background whereby in such a context, one's "genetic identity" entails knowledge about their genetic parents (or the individuals who contributed to their conception) and the mode of conception (see, e.g., Frith 2001, 480). A right-to-know is often linked with one's narrative identity interest and it is this interest that we would like to highlight in the regulations of HGE. In this section, we first set out the conceptual grounds for a right-to-know. We then argue for a right-to-know for the prospective children born via HGE based on a narrative account of identity. We explain how narrative identity should be conceptualized in the context of HGE and why it deserves ethical and legal attention as part of governance of HGE.

2.1 The conceptual basis for a right-to-know for prospective children born via HGE

In order to plausibly establish the claim for a right-to-know in the context of HGE, it must first clarify what information is at stake and the need for disclosure of such information. Unlike 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 circumstance without involving gamete/mitochondrial DNA donation from a third party). Thus, what is more relevant and pertinent for the resulting children in the case of HGE is to discover the fact that the child has been genetically modified prior to conception. We argue that children should have a right-to-know such information (and thus be free from deception [Marshall 2009, 135]) 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 birth.

Drawing from the theories on a right-to-know in the context of adoption, paternity proceeding and third party assisted reproduction (except for the case of MRT, which will be dealt with more details shortly), at least three (overlapping) grounds are applicable for a right-to-know for the prospective children born via HGE. Firstly, children's right to information has gained legal and judicial recognition as part of human rights. In particular, such a right is protected as an aspect of privacy rights through Article 8 of the European Convention on Human Rights (see, e.g., *Gaskin*'s case [1989]; *Mikulic* 's case [2002]; *Odievre* 's case [2003]). Secondly and relatedly, the international as well as UK law have widely recognised the significance of personal development, including the formation of self-identity (see, e.g., *Rose*'s case [2002]). As such, establishing personal identity is seen as part of one's private life with the formative function of identity also emphasized. Thirdly, the ascertainment of truth is generally seen as a good practice in serving the interest of children (see, e.g., *Re T* [2001]; *Re F* [1993]). Cowden (2016, 101) 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". This is based on the understanding of "recognition respect" which confers respect on children as children and as "an identity-holding entity"; not just the future adult they are becoming (Cowden 2016, 101-102).

Drawing from the above grounds, we argue that there should be a right-to-know for the prospective children born via HGE on the ground of narrative identity interest (more below). This differs from the approach adopted in the UK MRT debate. It is worth elaborating on this matter to draw lessons for the HGE debate. The UK policy making process in the mitochondria debate is led by the argument that mitochondrial genes are qualitatively and quantitatively insignificant in developing the resulting child's personal and physical traits (Appleby 2018). In its consultation process, the Human Fertilisation and Embryology Authority ("HFEA") (2013, para 6.69) highlighted in its advice document to the UK Government that the general permissibility of the technique is, inter alia, based on the (presumed) insignificant amount (that is about only 0.1%) and role of mitochondrial DNA[7] in an individual's overall genetic constitution. Following the advice from the HFEA, the UK government concluded that mitochondrial DNA does not affect the personal traits of children (DoH 2014a & 2014b). This eventually led to the final decision to allow MRT in the clinical setting.[8] This narrow "scientific" conceptualization of the genetic identity in the UK regulatory debates also led to other consequences which affect the rights of the individuals who donate and who are born as a result of MRT: the former have a right to anonymity and the latter thus have no right to identifying information about the donor.[9]

The consequences arising from such conceptualization of "genetic identity" has led to considerable academic debate. The primary criticism is that there seems to be an inclination to genetic essentialism in the UK government's reasoning, in the sense that a seemingly small contribution of mitochondrial DNA does not affect "who you are". Turkmendag (2018, 74) describes this as a "calculus of genes" – a form of reasoning based on "a percentage of calculation of DNA". Turkmendag (2018, 57) warns that this genetic-nature basis should not be given "privileged standpoint" as to the effect of how human rights are accordingly granted. This resonates with Wolf's (1995, 350) notion of geneticism, albeit in a slightly different context,[10] in which she cautions against the harm of geneticism where it signifies the use of genetic conceptions to construct and support power relationships – some dominate and others are deemed inferior. This seems to have happened in the mitochondria debate. Mitochondria donor-conceived children are arguably subordinated to those born as a result of gamete-donation because mitochondrial DNA donated by a third party is deemed to have an insignificant effect on the resulting person's overall identity and thus the right-to-know (genetic parents) as established in gamete donation is not extended to mitochondrial donor-conceived children (Turkmendag 2018).

Although, as we pointed out earlier, it is not the third party information that is the concern for HGE, the lesson that we would like to draw from the MRT policy debate is that an individualistic genetic-based account of identity – one which has dominated the MRT debate – should not be adopted in the context of HGE. Rather, we argue for a right-to-know one's genetic identity based on narrative identity interests. We now elaborate on how we conceptualize narrative identity in the context of HGE by laying out the main characteristics of narrative identity. Subsequently, we discuss the role of the information (that is, the fact of being born genetically modified) on one's narrative identity and further explain the ethico-legal implications of narrative identity derived from getting the information on the resultant children.

2.2 Conceptualizing narrative identity

This conception of "identity" has been widely applied in social science (see, e.g., Somers 1994; McAdams 2011). While this article cannot provide a comprehensive account of "narrative identity",[11] it draws attention to several main characteristics commonly referred to as a narrative account of identity. Narrative identity can be formed via storytelling – we construct our stories to make sense of our life (Scully 2017, 39; NCB 2012, para 4.7). Although this story is constructed internally, it is relational in the sense that we construct our story according to not only our own view, but also others' perception of us (Scully 2017). 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, genetic makeup and biological characteristics (Postan 2017, 81-82). As these factors are constantly changing, so are our narrative identities.

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 as perceived by the society, which could include the policy makers (Haimes and Timms 1985, 77, albeit in the context of adoption). For instance, how the media reports the use of HGE will likely have a plausible impact on the self-conception of the resultant child (Scully 2017, in the context of MRT). 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).

In short, we conceptualize narrative identity as follows: it is in the form of self-conception (storytelling) and it is dynamic. Narrative identity is not over-individualistic considering its relational construction in that it may be influenced by the third-party view and external factors. Noting this, the claim made here 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 (de Melo-Martin 2014, 33) because our 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 a coherent narrative. We agree with Ravitsky's (2014) view that defending a right-to-know certain information does not imbue any necessity to that piece of information. However, only if the information can make a significant difference in one's life, is defending such a right meaningful (Ravitsky 2014). 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).

2.3 The roles of information on narrative identity and the ethical weight of 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. Firstly, it promotes coherence – knowing one has been genetically modified before birth is pivotal for the resultant child in contributing (again, not determining) his/her self-conception and to make sense of his/her 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 (Postan 2017, 41). The knowledge of our circumstance of birth is considered as our past or personal history. This information of the past helps to connect the dots and justify why we take certain actions (Somers 1994, 616). Apart from health and safety concerns to individuals and the population, such a piece of information is so important for the individual child to make sense of him/herself, especially when the body is experiencing some unusual conditions due to the complexity of HGE (see, e.g., Gyngell, Douglas & Savulescu 2017, 504-506).

Secondly, it ensures authenticity – if one's self-narrative were formed due to false information, one may develop a distorted identity (Bluestein 1999, 23). Authenticity can be loosely defined as being true to ourselves (Varga and Guignon 2020). Being "true" to ourselves can be seen in two aspects. First, it relates to self-determination, which may be understood as being the author of our life as we define ourselves and are in control of our stories (Marshall 2009, 99). 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" (Marshall 2009, 99). Knowing the real "us" thus directs us "to realise" what we already are (Marshall 2009, 99). It is the latter that this article is concerned with in the context of HGE. Inaccurate beliefs about the past may undermine the individual making sense of their physical and social environment, therefore compromising his/her capacity to create a trustworthy autobiography (Bortolotti and Sullivan-Bissett 2018, 263; Postan 2017, 83). Lillehammer (2014, 106) observes that although everyone may be aware 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 belief that one's knowledge of these origins is accurate or complete". 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" (Lillehammer 2014, 107).

Additionally, the right-to-know the truth is an essential condition of being autonomous. This is indicated by Spranzi and Brunet (2014) 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. Phillips (2007, 105) 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.” 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 (Lamport 1988), thus promoting one’s autonomy (Scully 2017, 42). In the context of HGE, 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 use of HGE is to prevent the transmission of a genetic disease, resultant individuals also deserve to know the medical history that led their parents to use HGE. This, in turn, also affects how they construct their narrative identity.

Therefore, we stress that this conceptualization of “genetic identity” deserves greater attention from policy makers in the context of HGE. This is because such a right, if successfully established, may be a way to safeguard the interests of children born as a result of the procedure due to the impact this could have on the children’s sense of identity. This is further strengthened with the health and safety reason, particularly because of the yet-to-know implications of the procedure.

Conclusion: Summary and Further Research

The work done in this article could serve as a starting point for further research necessary for the governance of HGE. This article explored two conceptualizations of “genetic identity” relevant to the HGE debate. First, drawing from the current international provisions, we argued that a right to retain genetic identity cannot be soundly established due to both conceptual and practical ambiguities. Hence, such a right does not constitute a valid basis to determine the legality and ethicality of HGE. We highlighted that “genetic identity” in this context is best interpreted as to protect human (species) identity or the humanity. We therefore suggest further conversation on questions related to “preserving humanity” in the context of HGE.

Second, in relation to responsible translational pathways of HGE, we argued that a right-to-know the genetic identity (that is the circumstance of birth) should be given more weight in the regulatory debate of HGE with the focus on narrative identity interests. The protection of such interests would require disclosing accurate and truthful information about the fact of conception to the children. However, we have yet to discuss the details of how to implement and enforce a right-to-know in the context of HGE and its wider implications on other mode of assisted reproduction. It is worth stressing that there is currently no definite structure which legally enforces a right to be told the method of conception (as compared to a right-to-know the identifying or non-identifying information about the third-party donors in reproduction) (Frith 2011). This raises another research area worthy for further examination.

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[1] Scientist He Jiankui is charged of "illegal medical practice" and has been sentenced to three-year imprisonment and a fine (Nature News, January 3, 2020).

[2] Note, whether the clinical application of HGE can be categorized as "therapeutic" remains contentious. For instance, Mills (2020, 129) observes that the claim for "therapeutic" use in the context of HGE is misleading because the technique does not treat an existing individual but rather bring an individual with certain preferred characteristics into existence.

[3] MRT involves replacement of unhealthy mitochondria with a healthy one from a third party. In the UK, it is used to prevent the transmission of serious mitochondrial diseases. Note, it has been argued that "mitochondria replacement technique" is a misleading language when the procedure is in fact a "nuclear genome transfer" (see, e.g., Nisker 2015).

[4] "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.

[5] According to Juth (2016, 418), genetic determinism connotes the view that "a person is a product solely of his genes" and other factors such as the environment become less significant. A closely related concept is genetic essentialism that is the view that genes "determine the essence of who we are". These concepts, although 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" (Gericke et al. 2017, 1224-1225).

[6] Article 1 of the Universal Declaration on the Human Genome and Human Rights 1997.

[7] It is worth noting that although mitochondria are commonly known as energy provider to the cells (thus providing the UK government with the justification that mitochondria play only a minor role in identity), this is open to dispute. For instance, McBride, Neuspiel and Wasiak (2006) suggest that there are extended roles carried out by mitochondria which include directing and controlling of cell cycle which eventually affects body capacity.

[8] See, The Human Fertilisation and Embryology (Mitochondrial Donation) Regulations 2015.

[9] Ibid, Regulation 11(c); section 31ZA(2A) where it provides that only non-identifying information of the mitochondria donors is allowed upon request.

[10] 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".

[11] For a brief overview of different theories of narrative identity, see for instance, Cho (2018); Blasi and Glodis (1995).