GERMLINE EDITING: INTERVENING IN PARENT-CHILD RELATIONSHIPS

An analysis of Rehmann-Sutter's biology and phenomenology of the germline and the argument of relationality

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Abstract

The mainstream bioethical discourse on *germline editing*, intervening in the genome of a human embryo, has tended to focus on arguments of safety, benefits, autonomy and social justice, and to be universalist in kind. Rehmann-Sutter has recently argued that attention should be paid to the lifeworld and relational perspective of parent and child, because they will be most directly affected by the technology. In this thesis, Rehmann-Sutter's argument of relationality, which holds that what is morally troublesome about germline editing is that it might negatively change the parent-child relationship, is critically discussed. Rehmann-Sutter bases this argument on a theoretical framework that takes into account a biology and phenomenology of the germline. The germline is conceptualised as a vulnerable entity that is the embodiment of the relationship between generations, relating them backwards and forwards in time. While Rehmann-Sutter's claim that germline editing burdens the parents with a plethora of choice is rejected, it is argued that germline editing might be experienced by parent and child as intrusive in a manner that other reproductive technologies might not be. It is concluded that, in opting for germline editing, parents should make a decision that allows for a loving parent-child relationship to be maintained.

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Introduction

"My body was not 'built' by my parents and the genome was not 'written' by them. I am glad, otherwise I would perhaps blame them for all the mistakes and limitations within it. It was rather the nature of their bodies that created my body." (Rehmann-Sutter, 2010, p. 13)

A baby's body is born from her parents' bodies. And human intervention in the genetic structure of this new-born's body might complicate her (future) relationship[1] with her parents. She might blame her parents for the choices they made. This is an intriguing worry that does not stand on itself. The idea to manipulate the human appearance and capacities during its conception has fascinated and frightened novelists for centuries. Take for example the Greek myth of Prometheus who moulded men from clay, the horror inflicted by Frankenstein's creature or Huxley's dystopia picturing an embryonically manipulated class system[2].

CRISPR-babies

Such worries, however, are becoming particularly relevant now that intervening in the genome of the human germline is likely to become reality soon[3]. It might even already be reality today. As headlines have reported worldwide, in November last year, the Chinese scientist He Jiankui claimed to have orchestrated the birth of the world's first two genome-edited baby girls, modified to become HIV-resistant (Cyranoski & Ledford, 2018). While the procedure was not legally authorised, and the success of his attempt still has not yet been confirmed, the incident shows that indeed germline editing is on its way. It is the result of developments that started in 2012 with the discovery of the CRISPR-Cas system. This molecular system has since been developed into a laboratory tool that allows to edit the genome of virtually any organism with high accuracy (Doudna & Charpentier, 2014). It is likely one of the major technological advances of the twenty-first century to date. And with the advance in CRISPR-Cas, it has also become a real possibility to make precise and heritable changes to the genome of human embryos, thus interfering in the human germline.

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[1] Throughout this thesis, I will reserve the term *relationship* for interpersonal relationships specifically and use *relation* for all other usages of the term.

[2] This is a reference to the classic novels *Frankenstein or the Modern Prometheus* by Marry Shelley, 1818 and *Brave New World* by Aldous Huxley, 1931.

[3] Part of this introduction is based on an essay that I wrote earlier on the ethics of using germline editing to lower the genetic susceptibility to Alzheimer's disease, for a course on Medical Ethics and Practical Philosophy as part of the master programme Applied Ethics at Utrecht University.

Unsurprisingly, over the past years, germline editing has attracted much attention among the public, as well as amongst academics and policy makers. The rise of CRISPR-Cas has rekindled the debate on the need and permissibility of intervening in the human germline with new fervour: Popular journals and magazines report frequently on the topic of 'CRISPR babies' (Voormolen, 2019); academic journals publish position statements by scientists[4], ethicists and legal scholars, some calling for a moratorium on the use of CRISPR-Cas in human embryos (e.g. most recently Lander et al., 2019); advisory bodies bring out reports on how governments should respond (e.g. Nuffield Council on Bioethics, 2018). Actors from all these fields even gathered in Hong Kong, in November last year, during the large Second International Summit on Human Genome Editing, to try to reach international consensus on how to proceed (Dzau, McNutt, & Bai, 2018).

Throughout this commotion, a recurring pattern appears in the arguments that are brought up in the debate. Roughly, the debate is divided in two camps, represented by those optimistic about what the technology may bring us, and those fearful about it (Cavaliere, 2018; Gyngell, Douglas, & Savulescu, 2017; Van Dijke et al., 2018). Optimists argue that, once the technology is safe enough, carriers of severe genetically inheritable diseases should get access to germline editing in order to conceive a healthy[5], genetically related child. After all, parents are generally allowed to decide themselves what they consider to be best for their child (within the limits of social norms and social justice) and it is assumed that the child will benefit from not being ill. On the other side, those who object argue that the technique is unnatural, that it will never be safe enough, that it will lead to undesirable forms of human enhancement, or that it will harm the child's freedom to choose her[6] own path in life.

A relational perspective: Rehmann-Sutter

I have the impression that this current discourse based on considerations of risks, benefits, autonomy and equality does not succeed to get to the heart of the dilemma posed by germline editing. I have the intuition that germline editing might change something about the way the child will understand herself in relation to her parents, and how the parents will understand what they owe to their child. Most recurring arguments in the germline editing debate either focus on the parents and child as independent autonomous individuals, or on society as an abstract collective. They are, in other words, rather universalist in kind. Germline editing should however not be understood as a reproductive technology that stands alone, but as one that is

[4] Throughout this thesis, I will use 'science' and 'scientists' to refer to the *natural* sciences (often molecular biology in particular) and its practitioners.
[5] *Healthy* is meant here as not affected by the inheritable disease in question.
[6] Throughout this thesis, I will refer to children, parents and other individuals of whom the gender has not been specified, in their singular form, with the pronouns 'she' and 'her'.

embedded in society. The technology gains meaning in this social context, in which persons relate to each other. As the introductory quote shows, we may therefore wonder what human intervention in the genetic structure of a child might imply for the parent-child relationship. Such a relational perspective, which depicts parents and children in their real lifeworld, related to each other, is missing from the debate as I outlined it before. It seems therefore that the dominant discourse on germline editing does not cover all that is at stake. It needs to be asked what it means for parent and child to form a family, to care for each other, and to derive part of their self-understanding from that.

This is where the (hermeneutic) phenomenological approach of the Swiss contemporary philosopher Christoph Rehmann-Sutter, from whom the opening quote is derived, presents itself as an interesting alternative. He is interested in the role of genetics in human embodiment and human relationships. Recently, Rehmann-Sutter has made a promising attempt to construct a phenomenology of the germline (2018), exploring what role the germline plays in everyday and family life and how the germline is conceptualised through the lived experience of individuals. He wonders how the germline may be understood from the perspective of scientists as well as laypersons. He bases this on his earlier research into how individuals carrying a heritable disease and others in society regard and experience the idea of the genome and genetic relatedness and connects this to his own philosophy of biology and his anti-deterministic understanding of genetics. Rehmann-Sutter interprets the germline as the embodiment of the relationship between generations, connecting them backwards and forwards in time. He then uses this to argue that germline editing might affect intergenerational relationships and change the responsibilities that parents[7] have towards their future child. I will call this his *argument of relationality*. While the opening quote is taken from one of his earlier writings, it reflects his concern with germline editing quite accurately. I think that Rehmann-Sutter's perspective on the germline could be fruitful to complement the current bioethical discourse on germline editing and to draw attention to the argument of relationality.

Structure of this thesis

In this thesis, I will provide an in-depth analysis of Rehmann-Sutter's phenomenological approach towards the germline. The aim of my endeavour will be to shed light on the relational perspective on germline editing, which has largely been neglected in dominant bioethical discourse to date. The first two chapters of this thesis will be devoted to outlining the setting in which my argument takes place. In *chapter 1*, the

[7] Strictly speaking, persons with the wish and intention to conceive a child are *prospective parents*. Throughout this thesis, however, I will regularly refer to such persons simply as *parents*. I consider this to be appropriate as I discuss them in the context in which they contemplate themselves as the parents of their future child.

relevant technological aspects of the technology and its potential usages are discussed. In *chapter 2*, some attention is given to the ethical arguments that dominate the mainstream bioethical discourse on germline editing. This is meant to give an overview of the *debate to which I speak*, and to make clear from the start what the potential relevance of Rehmann-Sutter's argument may be.

The next two chapters will form a careful analysis of Rehmann-Sutter's thesis on the germline. To sketch the context of his argument, I will start out in *chapter 3* by discussing his theoretical background and the mixed methodology that recurs in many of his works. As will become clear, Rehmann-Sutter uses phenomenological hermeneutics as a basis for qualitative empirical studies into the lived experience of genetic technologies. Combined with a particular philosophy of biology, this informs his ethical reflections. I will to point out where the strengths and the weaknesses of this method lay. In *chapter 4*, I will proceed by discussing Rehmann-Sutter's recent thesis on the germline in detail. Here my aim will be to carefully dissect his argument into its constitutive elements, and put them in the context of his earlier writings. Roughly, his argument contains three parts: a biological view on the germline, a phenomenological view on the germline, and the ethics of germline interventions. I will provide a critical discussion of each, and use that to reconstruct his argument in what I consider to be the most fruitful manner. I will show that Rehmann-Sutter's thesis promisingly points out that it is the relationship between the parent and the child where something may significantly change due to germline editing. This is the *argument of relationality*. What it is that will change about this relationship has, however, been largely left open by the author.

In *chapter 5*, the last section of my thesis, I will draw out the implications of the argument of relationality on germline editing. I will explore the meaning of the parent-child relationship as an intergenerational and generative relationship, by drawing on sociological and phenomenological childhood studies. I will discuss care ethics to explicate the ethical dimension of family relationships and the responsibilities that flow from that. I will conclude that parents should aim to make a choice in which a loving parent-child relationship can be maintained. To this end, the parents will have to construct the narrative of their decision-making process which led them to opt (or not to opt) for germline editing. This will help them to be able to explain their choice understandably to their future child when she grows up.

Altogether, the aim of this thesis will be to show how Rehmann-Sutter's mixed biological and phenomenological analysis of the germline and his argument of relationality can be understood such that it may provide depth and nuance to the mainstream bioethical discourse on germline editing.

Chapter 1: CRISPR-Cas, germline editing and its potential applications

The aim of this chapter is to sketch the technical background of germline editing, against which the ethical and philosophical discussions of the rest of this thesis will take place. I will start by a general description of CRISPR-Cas technology. Then I will discuss some of the considerations that matter for its application as a reproductive technology. Finally, I will outline clearly with what types of germline interventions in mind I will proceed this thesis. Where applicable, the analyses and recommendations of the influential Nuffield Council on Bioethics of the United Kingdom (UK), as expressed in their recent publication *Genome editing and human reproduction* (2018), will be used as a guideline.

i. CRISPR-Cas technology

At the basis for the recent developments in germline editing is the discovery in 2012 of the bacterial immune system CRISPR-Cas[8], which is short for Clustered Regularly Interspaced Short Palindromic Repeats-Cas9 system (Jinek, Chylinski, Fonfara, Hauer, & Doudna, 2012). Cas9 is an enzyme that can be understood as a molecular scissor that is able to cut DNA in a precise and directed manner. The location of the cut is prescribed by an RNA fragment, the CRISPR sequence. What has made this discovery revolutionary, is that scientists have figured out how to manipulate the system in the laboratory. It is now possible to precisely predetermine the location of the cut and to insert new DNA fragments in the incision before pasting the DNA back together. This has turned CRISPR-Cas into a tool to make small edits in the genome of organisms ranging from bacteria, to plants, mammals and humans, allowing for small adaptations within genes or inserting whole new genes if desired (Doudna & Charpentier, 2014). Compared to classic genetic modification, CRISPR-Cas is less laborious, more precise and more widely applicable. Its better precision consists mainly in better control over the location of the insertion (i.e. less off-target insertions), and more control over the size and content of the insertion (e.g. the possibility of single-nucleotide changes, instead of inserting whole genes from other organisms).

Consequently, CRISPR-Cas has also revolutionised biomedical research, posing "unprecedented" possibilities for intervention in the *human genome* (Nuffield Council on Bioethics, 2018, p. xv). The first

[8] While CRISPR-Cas9 is the most promising and most well-known genome editing technology, alternatives, such as Zinc-finger nucleases (ZFNs) and transcription activator-like effector nucleases (TALENs), are being developed too.

gene therapies that will use CRISPR-Cas to correct for mutations in the *somatic (adult) cells* of human individuals afflicted with a genetic disease have entered clinical trials (Nuffield Council on Bioethics, 2018, p. 18). Moreover, the first scientific publication that reported the successful application of CRISPR-Cas to early *human embryos* appeared in 2015 (Nuffield Council on Bioethics, 2018, p. 35). Under current legal regulations, germline editing is only practiced for research purposes on early embryos (zygotes) who are discarded after use[9]. The consequences of the technique will become farther reaching when it will be *clinically* applied, as a reproductive technology, leading to the births of genome-edited babies, thus making heritable changes to the human germline. Such edits will affect not only one individual (the baby) but potentially many generations[10] to come[11].

Such application of CRISPR-Cas for reproductive purposes is often referred to as *germline editing*, because it will make heritable changes to cells of the human *germline* (as compared to somatic cells). A short note on this terminology is in order. Firstly, *germline editing* should be understood as an abbreviation of *human germline genome editing*[12], *germline* denotes a cellular lineage. Secondly, the term *germline editing* is not uncontested. The Nuffield Council for example prefers to circumvent the term altogether, speaking of *heritable human genome editing* instead[13] (2018, p. 2). Throughout this thesis, to refer to the use of CRISPR-Cas to edit the genome of a human embryo[14], I will stick to the term *germline editing* (or germline intervention). I will get back to this terminological dispute in my discussion of Rehmann-Sutter's perspective on the germline in *chapter 4*.

Notwithstanding the great promise of the CRISPR-Cas technology, it should be noted that scientific publications on its use in human embryos to date is limited, and that doubts about its efficacy and reliability remain (Nuffield Council on Bioethics, 2018, pp. 35–36). Two prominent worries relate to the risk of off-

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[9] The only known exception is the illegal case of Jiankui, which supposedly led to the birth of two genome-edited babies, as discussed in the introduction.

[10] The concept of generation may be understood in different ways. It may refer to a line of descent *within a family*, as stages in a family tree, or it may refer to *social decent*, to a group of people born at a similar time and place (Alanen, 2014). In this thesis, I use *generation* in the first sense of *family generations*. Generations in the second sense will be explicitly referred to as *social generations*.

[11] Whether the edit will indeed affect many generations or only one or few depends on whether the chromosome which carries the edit will be passed on or not. This is a matter of chance (about fifty percent chance for every child born from an individual carrying the edit).

[12] Following the Nuffield council (2018, p. 2), I will speak of *genome* editing rather than *gene* editing, although the terms are often used interchangeably.

[13] In contrast, the Dutch Health Council and COGEM speak of *germline genetic modification* in the English version of their report (or *kiembaanmodificatie* in Dutch) (2017).

[14] Note that next to editing early embryos, there are alternative situations through which germline edits could occur, namely when gametes (sperm and egg cells) are edited before conception, either intentionally prior to IVF, or unintentionally as a side effect of somatic gene therapy in an adult individual.

target effects (when the edit is made at the wrong location in the genome) and to the need to edit all cells of the embryo simultaneously (to prevent a *mosaic* embryo that will develop into an individual in whom only part of the cells in the body have been edited) (Nuffield Council on Bioethics, 2018, pp. 36–38). Nevertheless, when extrapolating the current developments into the future, the use of CRISPR-Cas technologies for germline interventions is likely to become safe for clinical use in the foreseeable future (Nuffield Council on Bioethics, 2018, p. 155).

ii. Possible applications of germline editing[15]

The great promise of germline editing is that it has the potential to prevent the passing on of a heritable disease from one generation to the next. It may therefore provide relief to individuals who know that they carry a genetic disease which they are afraid to pass on to their children. To set the stage for the potential usages of germline editing, a comparison with some other already available alternatives for individuals with the wish for a healthy child is insightful. Firstly, an interest in germline editing implies the wish to have a *genetically related* child. Without this precondition, child adoption as well as sperm or egg donation would provide available alternatives to these persons. Secondly, other reproductive technologies are already available in order to select a genetically related embryo unaffected by the disease, namely prenatal screening and pre-implantation genetic diagnosis (PGD). Prenatal screening of a naturally conceived child allows for the possibility to abort the pregnancy, thus preventing the birth of a child affected by the disease. PGD consists in genetic screening and selection of one of a number of embryos obtained through *in vitro* fertilisation (IVF). PGD is generally considered to be safe, and in most western countries it is available for individuals who wish to prevent passing on a severe genetic disease to their biological offspring.

Monogenic diseases

The near-future possibility of germline editing therefore becomes interesting only in those cases where PGD cannot provide relief[16]. For *monogenic* diseases[17], this could occur in the rare cases where IVF does

[15] Some of the technical knowledge discussed in this and other sections of this thesis are considered to be generally accepted knowledge and therefore no specific references are provided. As general resources see Alberts and Johnson's classic work *Molecular Biology of the Cell* (2014. 6th ed. Ww Norton & Co.) and the thorough report on *Genome editing and human reproduction by* the Nuffield Council (2018).

[16] Some authors have argued that germline editing might be preferable even if PGD provides an alternative (e.g. Cavaliere, 2018; see also Nuffield Council on Bioethics, 2018, pp. 45–46). I will get back to this in my discussion of Rehmann-Sutter's perspective on the germline in *chapter 4*.

[17] Monogenic diseases are those that are caused by a mutation on a single gene. A specific subset of those are diseases caused by a point-mutation, i.e. a mutation in a single nucleotide (or 'letter'). In contrast, polygenic diseases complex and multifactorial, and can be only partly explained by genetic mutations, generally involving multiple genes.

not provide an embryo unaffected by the heritable disease. This could happen for example when *both* biological parents are *heterozygous*[18] for an autosomal dominant[19] genetic disease (resulting in roughly twenty five percent chance that an embryo is unaffected) [20], or when *one* parent is *homozygous* for an autosomal dominant genetic disease (resulting in almost no chance that the embryo is unaffected) (Nuffield Council on Bioethics, 2018, pp. 44–45). Under the current regulatory paradigm[21] for genetic diseases, once considered acceptably safe, germline editing is most likely to be considered first for application to such cases where PGD is not an option[22], and only if the disease is considered to be *severe* (Nuffield Council on Bioethics, 2018, p. 155).

Polygenic diseases and other traits

There are however other cases imaginable in which germline editing might be considered in the future. Most prominently, there is the more complex situation of *polygenic* diseases. Such diseases are caused by genetic as well as environmental factors, and normally multiple genes are thought to be involved. Germline editing could theoretically be applied to correct for several of these mutations at once (which is not possible through PGD), although this would be technically challenging (Nuffield Council on Bioethics, 2018, pp. 38, 46). Because of the multifactorial nature of such diseases, a germline intervention would overall lower, but not preclude, the chance that the future child would be affected by the disease. Additionally, germline editing could be applied not only to diseases, but to any trait for which genetic risk factors or susceptibility factors are known. For example, it is imaginable that it could be used to change the eye colour of an individual. Moreover, germline editing could not only be used for traits that could be naturally conceivable by the parents, but it could – in theory – also be used to introduce improved or new traits to future individuals, as long as genetic susceptibility factors are known (Nuffield Council on Bioethics, 2018, pp. 46–

[18] The human genome consists of 23 chromosomes, of which every individual carrier two (unidentical) copies in each cell: one from the father and one from the mother. An individual is heterozygous for a certain mutation if she carries the mutation on only one chromosome, and homozygous if she carriesthe mutation on both chromosomes, with roughly a fifty and a hundred percent chance respectively to pass on the disease to the offspring.

[19] An *autosomal dominant* disease is a monogenic disease caused by a mutation in a gene on an *autosomal* chromosome (all 22 chromosomes excluding the sex (X,Y) chromosomes), which causes the symptoms of the disease (phenotype) even if the individual carries the mutation in only one of her two copies of this chromosome (genotype). This in contrast to an *autosomal recessive* disease where symptoms only occur if the individual carries the mutation on both chromosomes. In case of an autosomal recessive disease, an individual with only one copy of the mutation would merely be a *carrier* of the disease.

[20] This applies to the case where both parents carry the same genetic disease, as well as where both parents carry a different autosomal dominant disease and they wish for a child with neither of those diseases.

[21] If not otherwise specified, the regulations in the UK and the Netherlands will be used as examples.

[22] It should be noted that any application of germline editing in the foreseeable future will rely on IVF and PGD in the process, to provide a number of embryos and select the one that was correctly edited respectively (Nuffield Council on Bioethics, 2018, p. 37).

47). This could include disease resistance, or, leaving the disease paradigm, improved sensory or intellectual abilities. This type of genome editing is often referred to as *human enhancement*.

Technical scope of this thesis

In the remainder of this thesis, I will not be concerned with the question of which of these particular germline editing applications might be deemed most acceptable. Still, I will proceed my discussion of germline editing having in mind cases of severe (mono- or poly-) genetic diseases where PGD does not provide an alternative. This is because, as said, it seems likely (or even inevitable) that germline editing will become allowed for at least some such cases once the technology is considered to be safe enough. It is therefore these cases of genetic disease for which my question – what germline editing may mean for the relationship between parent and child – becomes most urgent. Focussing on therapeutic applications will also allow me to leave aside the debate on human enhancement to the extent possible. Doing so is advantageous as human enhancement is a huge debate in itself that stretches far outside the discourse on germline editing[23] and that tends to distract from considerations applying to less farfetched germline interventions which have my interest here[24] (see also Rehmann-Sutter, 2018, p. 11).

Before exploring this in depth, in the next chapter I will first discuss the dominant bioethical discourse on germline editing.

[23] For example, also PGD would suffice to select the eye colour of a child (although it could only select one trait at once).

[24] Admittedly, there are many germline editing applications imaginable for which it may be unclear whether they should be understood as therapeutic and enhancing. The distinction between therapy and enhancement is however irrelevant to my thesis. What matters is only that I am concerned with applications that could imaginably become allowed in the foreseeable future, which is most likely to be the case for severe monogenic diseases.

Chapter 2: The mainstream discourse on germline editing

In this chapter I will to outline the arguments that dominate the mainstream bioethical discourse on germline editing. This will serve to sketch the background against which my later discussion of Rehmann-Sutter's thesis on the germline gains relevance. I will start this chapter by providing a concise overview of the arguments that, in my view, dominate the debate, structured according to the main actors in the debate (*section 2.i*). Next, I will point out some of the shortcomings of the debate and show why Rehmann-Sutter's perspective on germline editing may be valuable to complement it (*section 2.ii*).

i. Outlining the dominant bioethical discourse

The bioethical discourse on germline editing is multifaceted. Some influential arguments were introduced before the rise of CRISPR-Cas. More recent publications are however affected by the changing insights on the quickly developing CRISPR-Cas technology. Meanwhile, germline editing itself remains largely hypothetical, so that expectations differ of how it is likely to be used and what impact it will have. Moreover, many different stakeholders have voiced their opinions, all adapting their tone of voice to on the audience they have in mind. Altogether, rather than one clearly demarcated discourse, there might in fact be several overlapping debates. These debates are characterised by a large variety of opinions and perspectives. For example, a recent literature review identified 169 different reasons in favour or against germline editing (Van Dijke et al., 2018). Clearly, I cannot provide here a thorough discussion of all of these reasons. Instead, I will outline what I consider to be the most important arguments in the debate. I will do so based on a selection of three types of relevant contributions to recent bioethical literature on germline editing: joint position statements, governance reports and philosophical papers.

Position statements

Firstly, a number of position statements have appeared from the scientific community, often in corporation with bioethicists or actors from the corporate world (Baltimore et al., 2015; Bosley et al., 2015; Doudna, 2015; Dzau et al., 2018; Lander et al., 2019; Lanphier, Urnov, Haecker, Werner, & Smolenski, 2015). Virtually all of these authors call for international deliberation to reach consensus on how development of CRISPR-Cas as a reproductive technology should be regulated and recommend engaging the public in this deliberative process. Opinions on the prudence of developing germline editing for clinical usage differ. Some statements call for a (temporary) moratorium on research or clinical applications in order to reach agreement on the conditions under which it could be deemed permissible to proceed (Lander et al., 2019; Lanphier et al., 2015). Most authors also delineate a tentative list of such conditions, which always includes

most prominently the need to overcome *safety* risks related to off-target effects and efficacy problems (see *chapter 1*).

Policy reports

Secondly, government advisory boards and other professional bodies in many countries have produced reports to provide governance advice. This includes the prominent bioethical advisory board in the UK, who proposes the two principles that should guide ethical acceptability of germline editing: *welfare of future persons* and *social justice & solidarity* (2018, p. xvii). The first principle includes safety requirements and prescribes to act in accordance with the wellbeing of the future person who will have been edited. The second principle pertains to effects on other individuals in society, and requests equal access to the technology and measures to prevent discrimination (e.g. against persons with a genetic disease) to be in place. The National Academies of Sciences Engineering and Medicine (NASEM) in the United States (US) (2017) propose seven guiding principles, the first three (*promoting wellbeing*, *due care* and *fairness*) overlap largely with the Nuffield's advice. These are complemented by three principles to guide governance and research (*transparency*, *responsible science* and *transnational cooperation*) and a principle demanding *respect for persons*, which refers to personal choice and personal dignity (2017, pp. 11–12). The Gezondheidsraad (Health Council) in collaboration with the Commission on Genetic Modification (COGEM) in the Netherlands (2017) adds to these arguments special attention to the contested *status of the human embryo* and what this implies for research with and clinical intervention in the genome of embryos (2017).

Philosophical arguments

Thirdly, moral philosophers have contributed specific arguments to the debate on human reproduction (technologies) which also apply to the case of germline modification and therefore gained significance in the debate. In favour or reproductive interventions, Savulescu has proposed a principle of *procreative beneficence* which prescribes parents to pursue the best chances in life for their children (Savulescu & Kahane, 2009). He argues that, as reproductive interventions can help to promote the wellbeing of future individuals, such technological developments ought to be pursued and used for that reason. Granting that germline editing is likely to become save one day, this will then also be an argument in favour germline editing for therapeutic applications (Gyngell et al., 2017). Harris goes a step further and argues that germline editing should even be pursued to *enhance human capacities* above the baseline of what is considered to be normal human functioning, introducing new traits to improve the human species (Harris, 2015).

Other authors have argued against such interventions. Sandel for example considers any intrusive attempt of parents to perfect the capacities of their children to be a form of unjustified dominance of men over

nature (Sandel, 2007). While his reference to *hubris* and the giftedness of life is religiously inspired, he argues that his argument may also be understood in a secular manner. According to Sandel, our tendency to perfection erodes our solidarity with the fate of others and leads to an *explosion of responsibility* for parents as they leave less to chance and more to choice. Other philosophers have focussed on potential harm to the freedom of the child. In this vein, Habermas has argued that the contingency of the beginning of a person's life is crucial for her understanding of herself as a *free and autonomous agent* and as the author of her own life history. Habermas therefore objects to purposeful human interruption in processes of conception (see discussion by Nuffield Council on Bioethics, 2016, p. 68). This resonates also with Feinberg's idea of a child's *right to an open future*, which prescribes that children should be left free to choose their own path in life and their own perception of the good life. What types of germline editing would be deemed permissible based on this right has however been interpreted differently by different authors (Bredenoord, Dondorp, Pennings, & De Wert, 2011; Mintz, Loike, & Fischbach, 2018).

In contrast to what these philosophers seem to suggest, most mainstream voices in the germline editing debate consider the technology to be *permissible under certain conditions*, rather than being an outright obligation or prohibition. This implies that the final decision whether or not to use germline editing should be left up to the parents, which is backed up (though often implicitly) by a principle of *reproductive autonomy*. As a negative liberty, as it was originally developed by Dworkin, this principle protects individuals from interference in their reproductive choices from the state. In the context of reproductive technologies it may also be interpreted as a positive right to reproductive assistance (Nuffield Council on Bioethics, 2016, pp. 63–64).

Principlism

Notably, several of these publications identify principles to guide the ethics and governance of germline editing. This is inspired by the mid-level principlism of Beauchamp and Childress, who, some forty years ago, formulated the four well-known bioethical principles of respect for autonomy, beneficence, non-maleficence and justice (Beauchamp & Childress, 2009). These principles were supposed to be universal and reflect the main moral ideas that are shared by all human beings and should therefore be able to guide decision-making when moral dilemmas arise, in medicine specifically. While the four principles themselves are less often invoked nowadays, the spirit of *principlism* remains prevalent in bioethics today. As the above discussion shows, also in the debate on germline editing most arguments revolve around a limited number of principles (explicitly or implicitly), most importantly wellbeing, safety, freedom and social justice. Undoubtedly, these principles are valuable to start, structure, and guide the debate. But focussing too much

on them may limit the potential depth of the debate. I argue that the current principle-based discourse does not cover all that is at stake in the dilemma posed by germline editing. There are some considerations that have received too little attention.

ii. What is missing in the debate

As I have introduced before, one of the things that I think is missing in the debate is thoughts about the perspective of the prospective parents[25] and the future child. What would be the situation in which parents would consider adopting germline editing? How would a child understand herself, knowing she has been edited? More is at stake than mere questions of autonomy when parents make intrusive decisions on behalf of their future child. In opting for germline editing, the parents have to choose responsibly. It is likely that the relationship between the parents and the child will be affected one way or another. Articulating this will require to go beyond the traditional midlevel principles of bioethics. It is this line of inquiry that I would like to contribute to in this thesis.

In addition, I propose that there is another number of questions that require more attention in order to guide the germline editing debate in a fruitful direction. Although I will not attend to them in my thesis, I mention them here shortly because my argument may relate to them indirectly. First, some of the familiar ethical considerations need further scrutiny. For example, what level of safety will be needed to start clinical trials, i.e. what threshold of risk should be considered acceptable? How far should reproductive autonomy be reasonably understood to extent in the liberal, pluralistic democracy in which we live? Practical questions are posed by the variety of opinions regarding the status of the human embryo, such as the permissibility of interfering with early forms of human life or even creating it for research purposes. These questions need a feasible response. And to help address the fear that therapeutic applications will ultimately lead to enhancement, the likelihood that germline editing would ultimately become used for 'enhancement' purposes should be assessed. Secondly, regarding governance of the technology, we need to thoroughly examine the call of 'public engagement' and 'international regulation': how and to what end should the public be included in the debate, what would reasonable agreement consist in (what conditions should it meet), and how (if at all) could regulation on an international level be achieved? For all of these questions,

[25] For the sake of simplicity, I will assume the child to be born in a two-parent family, where both parents wish to be genetically related to the child. My argument could however equally apply to a family where only one parent wishes to be genetically related to the child but is e.g. homozygous for an autosomal dominant inheritable severe disease. This could be a single parent family, or a family where also non-biological parent(s) are present.

addressing parents and children in their real lifeworld and social context might also help to formulate proper responses, enriching them with the experiential knowledge of the people concerned.

In this chapter, I hope to have shown why new perspectives on both familiar and neglected arguments are needed in order to reanimate the discourse on germline editing. One of the considerations that have received too little attention so far is the relationship between parent and child. It is in this light that the relational perspective proposed by Rehmann-Sutter becomes of great interest. He uses phenomenology in order to attend to the lifeworld of patients with genetic diseases and their family members, and uses this knowledge about the meaning of the genome and the germline to inform his ethical reflections on germline editing. His phenomenological exploration results in the conclusion that germline editing might change the structure of the parent-child relationship. Rehmann-Sutter's approach is a welcome addition to the dominant bioethical discourse for two reasons. Firstly, he uses an unusual philosophic-theoretical approach to ethics which is grounded in *phenomenological hermeneutics*. This provides a new perspective on germline editing, which may illuminate questions that are largely unexplored by mid-level principlism and the traditional consequentialist and deontological theories of ethics. Second, he draws attention to the neglected *argument from relationality*: understood from the lived experience of the main persons involved, it is the *structure of the family relationship* between the parents and the child that may be affected by the germline intervention, and potentially negatively so.

The rest of this thesis will be dedicated to thoroughly exploring the philosophical structure and potential implications of Rehmann-Sutter's thesis on the germline, in order to illuminate the usually neglected relational perspective on germline editing. The next two chapters will discuss Rehmann-Sutter's work. Before elaborating on his writings on germline editing and parental responsibilities in *chapter 4*, I will first (in *chapter 3*) leave the topic of germline editing aside and examine Rehmann-Sutter's general methodology and theoretical background. This will serve to provide the framework within which Rehmann-Sutter's thesis on the germline can be best understood.

Chapter 3: Rehmann-Sutter's theoretical background and mixed methodology

Rehmann-Sutter is a scholar with a mixed academic background in the natural sciences, social sciences and humanities. He was originally educated as a molecular biologist (degree 1984, University of Basel, Germany), and then made an academic turn through graduate education in Philosophy and Sociology (degree 1988, University of Freiburg im Breisgau, Germany) and a doctoral dissertation in Philosophy (degree 1995, Technical University of Darmstadt, Germany), to finally establish himself as bioethicist, in who's capacity he became president of the Swiss National Ethics Commission of Human Medicine (2002-2009). Currently, he is associated with the University of Lübeck (Germany) as Professor of Theory and Ethics in the Biosciences ("Christoph Rehmann-Sutter," n.d.).

A thorough interest in and understanding of *genetics* forms the *leitmotiv* of virtually all of Rehmann-Sutter's scholarly works. As an *ethicist*, he is concerned with moral questions surrounding genetic technologies. As a *phenomenologist*, he investigates what meaning is ascribed to the genome and genetic inheritance through the lived experience. And as a *philosopher of science*, he is interested in evaluating the scientific paradigm of contemporary genetics. As we will see in the next chapter, this three-partite methodology also characterises Rehmann-Sutter's thesis[26] on the germline (2018): here he develops a *biology of the germline* and a *phenomenology of the germline* as a basis for his *ethical evaluation* of germline editing. While biology, phenomenology and ethics are seemingly separate endeavours, Rehmann-Sutter seems to be dedicated to connecting them together into one overarching framework. The aim of this chapter will be to clarify how this is done and to evaluate whether it succeeds. This will serve as a preparation for understanding Rehmann-Sutter's thesis on the germline in the next chapter.

In short, Rehmann-Sutter's mixed methodology contains the following facets, and tends to start from a distinction between two perspectives on genetics: a scientific perspective and a phenomenological perspective. His *philosophy of biology* scrutinises the scientific perspective on genetics and formulates a critique on genetic determinism. His *phenomenology* explores how the genetics is understood from the lifeworld of individuals. To scrutinize the impact that the life sciences have on the lived experience of the people that it affects, he performs *socio-empirical studies* for which he combines phenomenology with

[26] I use the phrase *thesis on the germline* to refer to Rehmann-Sutter's combined phenomenological, biological and ethical approach to the germline and germline editing.

hermeneutics. *Hermeneutics* also allows him to study and explain how biology and phenomenology constitute different ways of interpreting worldly phenomena, including genetics. Finally then, his empirical studies of the lifeworld of individuals, together with a scientific understanding of genetics, inform Rehmann-Sutter's *ethical evaluation* of the use of modern genetic technologies.

In other words, Rehmann-Sutter has developed his academic niche by combining the following disciplines: (philosophy of) biology, phenomenology, hermeneutics, qualitative socio-empirical studies and (empirical) ethics. In this chapter I will discuss each of these facets of Rehmann-Sutter's methodological cocktail. I will start with his philosophy of biology and his critique on genetic determinism (*section 3.i*). Then I will discuss the phenomenological tradition and show how Rehmann-Sutter uses this to perform qualitative empirical studies into the meaning ascribed to genetics in the lived experience of lay persons (*section 3.ii*). Next, I will scrutinize how Rehmann-Sutter relates the lifeworld of individuals to the biological sciences, and especially what role hermeneutics plays in this (*section 3.iii*). Then I will discuss how this forms the base for Rehmann-Sutter's bioethics (*section 3.iv*), and I will finish with a short reflection on how all these parts relate to each other (*section 3.v*). Throughout I will aim to point out the promising aspects of his methodology as well as parts that are unclear. Overall, the discussion in this chapter is aimed to prepare my discussion of Rehmann-Sutter's thesis on the germline in *chapter 4*.

i. Rehmann-Sutter's scientific view on the genome

As said, fundamental to Rehmann-Sutter's phenomenology and ethics is his philosophy of biology and genetics. Rehmann-Sutter interprets the lived experience of the genome always against the background of a scientific understanding of genetics and a critique on genetic determinism. Understanding these is therefore crucial to understanding his phenomenological approach. For that reason, in this section I will recapitulate the main aspects of his philosophy of biology. I will first discuss his distinction between the *poiesis* and *praxis* view on developmental biology, and then explain how this relates to his critique on genetic determinism.

The organic practice view on developmental biology

In 2006, Rehmann-Sutter has published a philosophical work on developmental biology which forms the basis for his recent biology of the germline, as we will see in the next chapter. In this publication (2006), he proposes a new way of understanding developmental biology, based on Aristotle's distinction between *poiesis* and *praxis*. *Poiesis* is an activity with an external end-goal, while *praxis* is an activity where the process is the goal itself. Usually, developmental biology is understood by scientists in the former manner, as *poiesis*:

each cellular element (e.g. protein, nucleotide) has a function which is instrumental to the aim of the developing organism, namely to reach its adult form. Rehmann-Sutter argues however the adult form of an organism has no *ontological* priority (relating to the nature of being) over any other step of the developmental process. He sees development as a process with intrinsic significance, as an expression of the organism's continuous and changing presence in the world. Therefore, he proposes to view the development of organisms as a *praxis* instead. This is the *organic practice* view on development. It emphasises that each developmental step emerges from the environmental context created by the step before. Development is a sequential process, but it does not have a predetermined end-goal (2006). This argument is summarised in *row a* of *table 1*. The *organic practice* view informs Rehmann-Sutter's understanding of genetics, and as we will see in the next chapter, it informs his view on the germline too.

Table 1. *This table depicts the analogous biological claims of Rehmann-Sutter regarding development, genetics and the germline of organisms. The remark marked with an asterix (*) is my interpretation of Rehmann-Sutter based on the analogy set out in this table.*

		Deterministic view		**Preferred view**	**Ontological implications**
(a)	**Development**	***Poiesis* / Biological functionalism**	→	***Praxis*/ Organic practice**	
	(Rehmann-Sutter, 2006)	Developmental processes as instrumentally important to the functioning of the organism		Developmental processes as intrinsically important as an expression of the organism's continuous presence in the world	The adult form has no ontological priority over other stages of the developmental process
b	**Genetic information**	**Genetic programme**	→	**Biological system**	
	(Rehmann-Sutter, 2006; 2008)	DNA as the carrier of genetic information, blueprint of the organisms development		Genetic information arising from the complex cellular and environmental interactions of which DNA is only one aspect	The DNA has no ontological priority over other components of the cell or environment
(c)	**Germline**	**Continuous lineage**	→	**Corporeal intergenerational nexus**	
	(Rehmann-Sutter, 2018)	Germline as a continuous and stable lineage from which the bodily presence of every individual in each generation arises		Germline as a fragile entity that passes through and is dependent on the body of every individual in each generation	The germline has no ontological priority over the bodily development of the individuals of each generation*

As a side note, let me remark that Rehmann-Sutter has declared that his *organic practice* view has a metaphysical implication, namely that a deeper meaning might be embedded in the presence of living organisms in this world, a meaning that might not be accessible to human comprehension (Rehmann-Sutter, 2006, pp. 322–323). This repeated assertion gives a spiritual undertone to his philosophy, one that I will however not attend to any further in this thesis.

A critique on genetic determinism

According to Rehmann-Sutter, the view of development as *poiesis* has been especially dominant in the field of genetics, which has his particular interest (Rehmann-Sutter, 2006). This led to the *genetic programme view* on genetics, which regards DNA as the essence of life, the master molecule containing the instructions for the development and architecture of an organism. Rehmann-Sutter objects to this *essentialist* or *deterministic* reading of the role of DNA in living organisms (2016). His proposed understanding development as a *praxis* provides an alternative interpretation: it is the dynamic *interaction* between DNA and other cellular and environmental elements that lead from one developmental step to the next. Genetic information only becomes *significant* information in the cellular context of the organism, so that the genotype (the genetic structure) does not simply predetermine the phenotype (the physical structure) of an organism. In short: DNA has no ontological priority over other elements (Rehmann-Sutter, 2008). A picture emerges of the organism as a macromolecular, (multi)cellular and dynamic system, in which DNA is only one of the players. Rehmann-Sutter advocates this *systems view* on biology in many of his works (Rehmann-Sutter, 2002, 2006, 2008, 2010, 2018; Rehmann-Sutter & Mahr, 2016). For an overview of the analogy between *systems genetics* and *development as praxis*, see *row a* and *b* in *table 1* below.

The significance of systems biology

Rehmann-Sutter asserts that the genetic programme versus systems view should be regarded as two alternative modes of sense-making of living beings and biological systems, as alternative *hermeneutic* hypotheses (Rehmann-Sutter, 2006, 2010). Critics have remarked that Rehmann-Sutter's anti-determinism might be overly sceptical, because such strict determinism is hardly endorsed by any contemporary genetics (Pridmore, 2008). According to Rehmann-Sutter, his discussion of systems biology matters however also outside the realm of science. He argues that the faulty genetic programme view predominated science in the first decades following the discovery of the structure and functioning of DNA and that today it still informs much of media covering, public discourse and layman's understanding of genetics (Rehmann-Sutter, 2008, 2010).

For Rehmann-Sutter, the scientific and the layperson's understanding of genetics are closely connected, as becomes clear from his repeated parallel discussion of the two in many of his publications (Rehmann-Sutter, 2002, 2006, 2008, 2010, 2018; Rehmann-Sutter & Mahr, 2016). Before discussing how the relation between the two should be understood, which is complex and sometimes diffuse, I will now turn to Rehmann-Sutter's phenomenological investigations of the genome.

ii. Rehmann-Sutter's phenomenological exploration of the genome

In addition to the scientific view on genetics, Rehmann-Sutter is interested in how genetics is experienced in everyday life. He wonders what a genome may mean for "those who have it in their bodies and who *live* it" (emphasis original; Rehmann-Sutter & Mahr, 2016, p. 87). In particular, he takes an interest in the role that scientific knowledge of genetics and genetic diseases, and the genetic technologies that flow from it, play in the lives of the individuals confronted by it. As the experts of their own lifeworld (Rehmann-Sutter & Mahr, 2016, p. 87), these laypersons[27] are put at centre stage of Rehmann-Sutter's *phenomenological* investigations. Phenomenology is a method of studying how worldly phenomena are perceived, and gain meaning, through human experience (Rehmann-Sutter, 2018, p. 14). Therefore, phenomenology is particularly suitable to exploring how the genome is understood through the lived experience of individuals. To study this empirically, Rehmann-Sutter uses a particular hermeneutic-phenomenological approach.

In this section, I will first point out some of the general features of the phenomenological tradition that are of importance to Rehmann-Sutter's works. Next, I will detail how he combines this with hermeneutics to perform qualitative empirical studies into the lived experience of the genome.

Phenomenology, embodiment and the lived experience of the genome

Phenomenology developed during the first half of the twentieth century as a descriptive and practice-oriented (or *praxis*-oriented) philosophy. The central idea of phenomenology is that the world should be understood not in an objective sense, but always as phenomena as experienced through human consciousness. It considers what we perceive in the world (phenomena), rather than how things are (Carel, 2011). Following Husserl, this is referred to as the *lifeworld*: the world as we are situated in it, as we experience it, as we take it for granted (Gallagher, 2012).

Central to the way an individual perceives the world and thus experiences life, is the human *body*. Phenomenologists have distinguished two different dimensions of the body: the *body as lived* (or: the *body we are*) and the *object-body* (or: the *body we have*). The first is the body as it is experienced from a first-person perspective. According to Merleau-Ponty, this body is the enabling condition of the entirety of our senses, of our subjective experience, and of our interaction with the world. It is therefore also central to

[27] In accordance, I use the term *layperson* or *layman* – as opposed to (medical or scientific) professional – not as someone lacking knowledge, but as someone with access to a different kind of knowledge (experiential knowledge instead of scientific knowledge).

our self-understanding. The second is the body as it is perceived from a third-person perspective, as the object of medical investigations (Carel, 2011; Düwell, 2012). Because of this focus on the corporeal aspects of the human experience, phenomenology (Merleau-Ponty's phenomenology specifically) has been influential in medical philosophy and in research into the experience of illness. The distinction between the object-body and the body as lived allows to understand illness as a disruption of the harmony between the two: illness attracts our consciousness to the bodily aspect of our existence of which we are normally only vaguely aware (Carel, 2011).

The idea of *embodiment* is relevant to Rehmann-Sutter's method also. In addition to the *body we are* and the *body we have*, he discerns a third bodily dimension: the *body we do*. This is the *enacted reality of our bodies*, for example the body as it is depicted through medical imaging technologies (Rehmann-Sutter, 2006). Rehmann-Sutter relates these three dimensions of the body to the lived experience of the genome in several of his publications, although in each he explains this relation somewhat differently (Rehmann-Sutter, 2006, pp. 327–329; Rehmann-Sutter & Mahr, 2016, p. 88). I propose that on this point Rehmann-Sutter can be best understood as follows. Clearly, as an object of scientific investigation, the human genome is part of the *object-body*. How it is part of the *body as lived* is less clear, as – unlike our limbs or our stomach (when it aches) – the genome cannot be perceived as a part of the body in everyday life. The genome is however accessible to the lived experience *as knowledge* (Rehmann-Sutter & Mahr, 2016). According to Rehmann-Sutter, each individual creatively interprets the (scientific and non-scientific) genetic information that is available to her. She imagines her genome as something that is partially comprehensible, but that may maintain a partially incomprehensible or mysterious dimension. Furthermore, Rehmann-Sutter has posited that this image of the genome co-shapes the lives of individuals with genetic susceptibilities as well as their families, and *affects the relationships between them* (Rehmann-Sutter & Mahr, 2016). Last, the genome also appears in the *enacted body*, for example through the outcome of genetics tests. For this reason, Rehmann-Sutter contends that "we *do* our genes" as we *do* our bodies (emphasis original; Rehmann-Sutter, 2008, p. 49).

Phenomenological qualitative empirical studies

Phenomenology thus matters to Rehmann-Sutter's work as an approach to philosophise the embodiment, situatedness and lived experience of individuals in the world, especially in relation to genetics. In addition to using it as a philosophical approach, Rehmann-Sutter uses phenomenology to inform his *empirical research* into the lived experience. The relationship between phenomenology and the empirical is however complex. While traditionally phenomenology is understood as a *transcendental* method that is explicitly not empirical,

some recent scholars have diverted from this view, and developed phenomenology into an empirical method (Carel, 2011; for a critique, see Schües, 2017, pp. 226, 236). Rehmann-Sutter joins this empirical turn and combines phenomenology with *hermeneutics* to perform qualitative empirical studies that investigate the meaning that is ascribed to genetic information through the lived experience (Rehmann-Sutter & Mahr, 2016; Rehmann-Sutter, Porz, & Scully, 2012). I will discuss this methodology here shortly.

Hermeneutics is the methodology of interpretation (Mantzavinos, 2016). Rehmann-Sutter uses *phenomenological hermeneutics* to perform interviews which aim to capture the meanings and interpretations given to genetics in the narratives of individuals (Rehmann-Sutter et al., 2012). In this method, the researcher tries to acknowledge several levels of interpretation in the interview process. The interview process can be explicitly understood as a *hermeneutic circle*, in which the participant (interviewee) searches for meaning in their own experiences, and the researcher (interviewer) searches for meaning in the narrative of the participant. The researcher unavoidably starts from her own background assumptions, and should try to explicate these to the extent possible. Moreover, the researcher is affected by her interaction with the interviewee through a process of understanding. Both are recognised as an actual part of the research process (Rehmann-Sutter & Mahr, 2016; Rehmann-Sutter et al., 2012). This strategy is in line with established qualitative empirical research methods like Interpretative Phenomenological Analysis (IPA) (Chapman & Smith, 2002). Rehmann-Sutter has used this method, for example, to reveal different coping strategies in the narratives of patients with genetic diseases: he found that some patients were overwhelmed by feelings of shame and guilt for their burdensome genetic endowment, while for others a feeling of individuals agency prevailed in spite of the genetic inclination of their disease (Rehmann-Sutter & Mahr, 2016).

Phenomenology thus plays a role in Rehmann-Sutter's philosophy as well his empirical studies, as a method to access the lived experience of the genome. In the next section, I will discuss how these phenomenological studies relate back to his philosophy of biology and his critique on genetic determinism.

iii. Hermeneutics: biology and phenomenology of the genome intertwined

It may be asked how the relation between Rehmann-Sutter's phenomenology and his philosophy of biology should be understood. In other words, it may be asked how the lived experience and the scientific

understanding of the genome relate to each other[28]. Unfortunately, Rehmann-Sutter himself is not very clear on this point. In several of his publications, he suggests that hermeneutics plays a role in this relation, but in each publication he explains this role somewhat differently. In what follows, I will discuss three of Rehmann-Sutter's explanations, and conclude by presenting what I consider to be the most plausible interpretation of how the life sciences, phenomenology and hermeneutics are related in Rehmann-Sutter's work.

Two hermeneutic perspectives

In "The Lived Genome" (Rehmann-Sutter & Mahr, 2016), Rehmann-Sutter presents biology and the lived experience as two complementary *hermeneutic* perspectives on (human) genetics. He discerns between the *biomedical genome*, i.e. the scientific description of genetics, and the *lived genome*, i.e. how genetic information is interpreted by the those carrying genetic mutations. These two genomes "represent two different but inter-related interpretative contexts of the genome, and at the same time two different levels of interpretation." (p. 92) In other words, the genome can be understood through science and through the lived experience, each providing a different but interrelated interpretation of it. Rehmann-Sutter further argues here that the scientific interpretation of the genome matters to the lifeworld as well the scientific world[29], albeit in a different manner. Scientific information about the genome needs to be translated in order to become meaningful to the individual (pp. 92-93). This happens through a process of *reflexive embodiment*. Again, Rehmann-Sutter does not clearly explain what he means by this. My understanding however is that reflexive embodiment is about actively and consciously reflecting on what our awareness of having a genome and having (limited) knowledge about this genome means for our understanding of ourselves as beings living in our bodies. *Reflexive embodiment* is the active process through which the lived genome and the biomedical genome relate to each other (Rehmann-Sutter & Mahr, 2016, pp. 88–91).

Metaphors

Elsewhere, Rehmann-Sutter affirms that the scientific view on genetics should be understood as a hermeneutic endeavour in itself: already in our description of living organisms and the human body, we

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[28] Rehmann-Sutter's colleague Schües also asks this question and criticizes Rehmann-Sutter for his (hermeneutic) approach to it. She has argued that molecular biology and the lived experience are two different discourses, and that the translation between them is an undertaking that is more complex than Rehmann-Sutter sometimes seems to suggest. "The language and understanding of biology and everyday life may marginally overlap. … Being knowledgeable in both discourses can help to switch languages. But a shift of meaning cannot be overcome." (Schües, 2017, p. 237). This second remark is a critique on Rehmann-Sutter that I quite share.

[29] Note that Rehmann-Sutter admits that this deviates from the traditional phenomenological understanding of the lifeworld as an essentially pre-scientific world.

interpret these processes (2006, 2010). This becomes clear from the metaphor of DNA as the *book*, *blueprint* or *code* of life, which falsely present DNA as the essence of life (with a God-given, men-made and machine-like connotation respectively) (Rehmann-Sutter, 2010). These metaphors might contain social and political as well as scientific meaning, because they are the product of human interpretation (Rehmann-Sutter, 2002, 2010). Moreover, through our embodiment, they might also affect the layman's understanding of genetics and genetic disease, and therefore her self-understanding and identity. Here it becomes clear how different scientific understandings of genetics might influence the lived experience. The *genome as a programme* depicts our embodiment as the result of our genes, and therefore genetic disease as a fault in them. But according to the *systems view*, our embodiment develops from our social, cultural, environmental *and* genetic context. This second view allows to see ourselves and others as *integral persons* with a body that is not predetermined by the genome (Rehmann-Sutter, 2002). Put in simple words, *we are not our genes*. This explains why, according to Rehmann-Sutter, the systems view on genetics matters to the lived experience of the genome too.

Five levels of meaning

In "Genetics, A Practical Anthropology" (2008), Rehmann-Sutter further details a gradual relation between the scientific and the phenomenological. Here, in the context of *genetic testing*, he discerns five levels at which genetic information acquires meaning to the potential user of a genetic test, ranging from biological on one side to experiential on the other (see *table 2*). At one extreme is the interaction of DNA with other biological and environmental processes (level 1). This is the level where the genetic information becomes significant for the body and may lead to bodily functions and dysfunctions. This is what the test is aiming to show. The next level (2) is the DNA sequence that is the direct subject of the genetic test[30]. Then follows the central level (3): the outcome of the genetic test and the way this test presents the genetic information. The manner in which the outcome of the genetic test, including the genetic risk factors, is understood by the user has implications for her perception of her own body. This is level 4. Lastly, this understanding of the body becomes meaningful in the social structure in which the user finds herself, and her relationships with those surrounding her (level 5).

[30] Note that, in line with Rehmann-Sutter's systems biology, DNA is not the starting point, nor the centre, of this scheme. DNA itself is merely one of the levels at which genetic information gains meaning.

Table 2. *Five levels of meaning of genetic information for the user of a genetic test, ranging from biological meaning on the left, to experiential and social meaning on the right (table retrieved from Rehmann-Sutter, 2008).*

What the body does		What people do		
1	2	3	4	5
Interactive processes between DNA and other factors generating developmentally significant 'genetic information' in the cells of the body	DNA sequences (a mutation, a 'gene')	Results of a genetic test	Hermeneutic framework for understanding the biological significance of genetic information in the body	Social complexities and processes of social interactions generating 'genetic information' from the perspectives of the actors

Importantly, Rehmann-Sutter notes that level 1 and 2 are the subject of scientific experimental investigation. Scientific interpretations of the genome also matter to level 4 and 5, but only through a process of interpretation. This is in line with what I have described so far. Rehmann-Sutter however further asserts that hermeneutic interpretative methods are needed to study level 4 and 5 (2008). This is strange for two reasons. First, he makes no mention of phenomenology (or phenomenological hermeneutic methods) in this publication, even if level 4 and 5 are clearly concerned with the lived experience of individuals. Second, describing *only* level 4 and 5 as the subject of hermeneutic investigations contradicts his other writings where he explicitly states that the scientific perspective on genetics should be subjected to hermeneutic investigations too (e.g. Rehmann-Sutter & Mahr, 2016).

The role of hermeneutics

Together, it is not always clear what role is ascribed to hermeneutics in Rehmann-Sutter's methodology. I propose that the most likely reading of his work is that hermeneutics, as the study of interpretation, is what connects the phenomenological perspective and the scientific perspective on the genome. Simultaneously, the subjective (or *lived*) experience of the genome, and the attempt towards an objective (or scientific) description of the genome, could be understood as hermeneutic activities in themselves. In line with this

interpretation, I suggest that of the five levels of meaning, level 1 and 2 are the topic of scientific investigation, level 4 and 5 of phenomenological investigation and level 3 relates to both. Hermeneutic interpretation is needed at each level, and also in order to understand to whole.

Understood this way, these five levels at which genomic information can be meaningful, show how, for Rehmann-Sutter, his systems biology and phenomenology are connected. For the body, genetic information only gains meaning in systemic processes (systems biology). For the individual, genetic information gains meaning in her own lifeworld and her social interactions with others (phenomenology).

iv. The ethics of genetics

Last, the hermeneutical understanding of the lived experience of and the scientific perspective on the genome relate to Rehmann-Sutter's work as a bioethicist. While this theme recurs in many of his ethical works, again, it is not immediately clear how this is so. I will first discuss the relation between ethics, phenomenology and his qualitative empirical studies, and then discuss if and how Rehmann-Sutter's philosophy of biology also plays a role in his ethics.

A phenomenologically informed hermeneutic approach to bioethics

Ethics may be defined as the field of philosophy that concerns itself with the question of what it means to act well and more broadly, what is valuable in a human life. In line with his concern with the lifeworld of individuals, Rehmann-Sutter approaches ethical questions from the perspective of everyday practice instead of starting from ethical theory. In other words, he takes a bottom-up instead of top-down approach to ethics and is a proponent of empirical ethics. This is a branch of ethics as a discipline that draws from empirical studies into the attitudes of people towards ethical dilemmas with which they are confronted in everyday life, in order to inform the ethical reflection of the philosopher. In particular, Rehmann-Sutter advocates what he calls a *phenomenologically informed hermeneutic approach to bioethics* (Rehmann-Sutter et al., 2012).

According to Rehmann-Sutter, ethical reflections of a bioethicist must account for the real-life world of the people concerned and the "experiential landscape of their situation" (Rehmann-Sutter et al., 2012, p. 436). He holds that ethical reasoning must be justified by a thorough understanding of the particulars of a situation, which is to be obtained by interacting as closely as possible with the first-person perspective of the people involved. Therefore, Rehmann-Sutter's ethical reflections embroider upon the qualitative empirical method of *phenomenological hermeneutics* that I described before. Practiced as a circular process, the researcher interrelates the empirical investigation of the lifeworld of the actors involved, with the

normative evaluation of what one *ought* to do in a given situation. As, however, the normative evaluation cannot *logically* follow from a descriptive investigation alone, in this method a crucial role for the ethicist remains in taking accountability for the validity of the ethical argument (Rehmann-Sutter et al., 2012).

In these studies, Rehmann-Sutter thus aims to interact with the lifeworld of individuals confronted by ethical dilemmas, and through a process of mutual interpretation and normative evaluation, he aims to reflect on the moral dimension of the dilemmas. This is roughly how his phenomenology, hermeneutics and ethics interrelate. Note that several authors have questioned the critical potential of phenomenology, especially its ability to formulate a *moral* critique (Düwell, 2012, p. 134; Whitehead, Woods, Atkinson, Macnaughton, & Richards, 2016, p. 11). This is because it is unclear how and for what reasons the ethicist may distance herself from the potentially flawed ethical ideas of her research participants. Rehmann-Sutter argues that he circumvents this problem by presenting his phenomenological hermeneutics as a mediating approach to bioethics, connecting the lifeworld of patients, practitioners, researchers and policymakers. He asserts that a phenomenological approach to ethics allows one to bracket questions regarding the existence of an objective world or an objective moral truth. Instead, it allows an understanding of ethics as a normative practice embedded in the social and real-life context of a subjective world (Rehmann-Sutter et al., 2012).

Biology and ethics

The relationship between ethics and Rehmann-Sutter's philosophy of biology is more complex. According to Rehmann-Sutter, for all the five levels of genetic meaning (see *table 2*), ethics comes in if we understand all these levels as practices (Rehmann-Sutter, 2008). For level 1 and 2 (i.e. DNA and its dynamic environment), this makes sense only if we follow the organic practice view discussed before (Rehmann-Sutter, 2006, 2008). It allows us to recognise our own subjective and bodily presence in the world, through which we observe or *witness* (after Merleau-Ponty) other living beings with whom we share our environment, and to think of them as having their own *subjective* dimension and intrinsic significance. According to Rehmann-Sutter, the *ethical* implication of these metaphysical assumptions is that they ascribe *responsibility to us in our relationship* with these organisms (2006), and with our own bodily developmental processes (2008). I regard this to be a rather implausible part of Rehmann-Sutter's philosophy, as it is not clear (nor does he explain) what these responsibilities would imply.

I propose that it is more plausible to view level 3, 4 and 5 as the proper topics of ethical reflection. These are the levels in which genetics gains meaning in the embodiment, lifeworld and social context of individuals. Therefore, they are practices that involve actors with intentional actions, who are faced with the ethical

complexities of the decision-making processes. These practices can be subjected to phenomenological hermeneutic investigations to draw out the ethics.

Moreover, I propose that it is at these levels that scientific interpretations of the genetics gain an ethical dimension. For example, the (semi-scientific) way an actor understands genetics has an impact on how she interprets the outcome of the genetic test (level 3), which may in turn impact the image that the actor has of her own body (level 4) and the way she will be treated by others (level 5) (Rehmann-Sutter, 2008). In other words, the depiction of the DNA affects how patients, doctors, politicians and others view the relationship between the genome, the body, and the self. Importantly, Rehmann-Sutter argues that this has implications for our ideas regarding responsibility. For example, if something 'is genetic', it may discharge the affected individual from some responsibility for supposedly related life events, and conceivably shift some responsibility in the direction of the physician in attendance (Rehmann-Sutter, 2008). This theme of responsibility also returns in Rehmann-Sutter's thesis on the germline, as I will discuss in the next chapter.

v. A multifaceted approach

Overall, it may be clear that Rehmann-Sutter's methodology has many faces. It seems that, over the course of his career, he has aimed to merge philosophy of biology, phenomenology, hermeneutics, qualitative empirical studies and ethics into one overarching approach. As I have tried to show, this mixed methodology is not always entirely convincing. Especially the proper place of biology in this method remains diffuse, with regards to phenomenology as well as ethics.

His mixed methodology is however also promising, for several reasons. Most importantly, his phenomenological investigations allow him to draw attention to a perspective that is often neglected, namely how the biomedical technologies developed in the sciences impact the lifeworld of the people who are confronted by it. It allows him to put patients, their families and others concerned at the centre stage of his philosophical reflections. Hermeneutics then provide Rehmann-Sutter the means to show that scientific knowledge is reinterpreted by these laypersons, so that it gains new meaning in their lifeworld. Qualitative empirical studies allow him to approach this first-person perspective as close as possible, for example to explore how genetic technologies change the relationships between people. His ethics, finally, reflect on the moral dimension of the insights gained through all these methodologies.

The understanding of Rehmann-Sutter's multifaceted methodology that this chapter has aimed to provide, will serve as the base from which, in the next chapter, I will discuss Rehmann-Sutter's thesis on the germline.

Chapter 4: Rehmann-Sutter's biology and phenomenology of the germline and the argument of relationality

In his recent publication "Why Human Germline Editing is More Problematic than Selecting Between Embryos: Ethically Considering Intergenerational Relationships" (2018), Rehmann-Sutter develops an intriguing view on the ethical issues arising from the soon possibility to edit to the genome of a human embryo. Like most other authors, he refers to this technology as *germline editing* (or *human germline gene editing* in full, see also *section 1.i* for a discussion of this terminology).

His philosophical endeavour in his article can be best interpreted as consisting of two halves: In the first, Rehmann-Sutter explores the meaning that is given to the concept of the *germline* from a biological as well as phenomenological point of view. This serves as "a theoretical framework for discussing the ethical questions of [human germline gene editing]." (p. 9) In the second half, Rehmann-Sutter uses this to discuss two (of potentially many) ethical issues that are raised by *germline editing*: what safety levels are required and how germline editing compares to PGD, with emphasis on the second issue. Note that this tri-partite methodology (scientific – lived experience – ethics) fits his in his general style and methodology as I have discussed it in the former chapter. Also with respect to the content, his thesis on the germline fits his earlier writings on the biology and phenomenology of genetics. My discussion of Rehmann-Sutter's prior work on scientific understanding and the lived experience of the genome, in *chapter 3*, will therefore aid the interpretation of his thesis of the germline as I will discuss it in this chapter.

While unfortunately the structure of his argument is not always clear (as I will get back to in *section iv*), I consider Rehmann-Sutter's thesis to be interesting because, in the course of it, he develops an interesting sub-argument: that editing the germline of a child may affect her (future) relationship with her parents, probably negatively so, and that this might change the *type of responsibility* that parents hold towards her. This is an argument that is not often heard in the germline editing debate, and I will refer to it as the *argument of relationality*.

To show how Rehmann-Sutter arrives at this argument, in this chapter, I will discuss those aspects of Rehmann-Sutter's thesis that I consider to be most relevant to his argument of relationality. Note that this does not necessarily correspond to the weight given to these sections by Rehmann-Sutter himself. For example, I will leave his ethical discussion of the safety requirements aside, and I will only shortly pay attention to the therapeutic assumption of germline editing. Moreover, while I will highlight the parts of his argument that are particularly unclear, overall, I will represent Rehmann-Sutter's thesis in the most plausible

manner. This means that I will recombine the parts of his argument in the order that seem to fit best, and that I will sometimes interpret what is implicit in his text, often based on my discussion of his earlier writings.

In this chapter, I will discuss Rehmann-Sutter's thesis divided into three parts: the *biology of the germline*, the *phenomenology of the germline* and the *ethics of the germline* (the first two phrases I borrow from Rehmann-Sutter directly, 2018, pp. 12,14). I will start with his biology of the germline, in which he depicts the germline as an entity that reaches through the body and that connects generations backwards and forwards in time (*section 4.i*). Then I will discuss his phenomenology of the germline, which he uses to explore what meaning the germline gains in the context of embodiment and in social and family relationships (*section 4.ii*). Third, I will discuss the ethical argument that Rehmann-Sutter draws from this, in the form of a comparison between PGD and germline editing (*section 4.iii*). Fourth, I will reflect on how the relation between the biology and phenomenology of the germline should be understood (*section 4.iv*). I will finish by recapitulating what I consider to be the most plausible interpretation of his argument in light of his argument of relationality (*section 4.v*). How the parent-child relationships should be understood in more detail and what this implies for the parental decision to opt for germline editing will be the topic of the next chapter.

i. The biology of the germline

Rehmann-Sutter's *theoretical framework* to explore the ethics of germline editing is composed of a biological and a phenomenological perspective on the concept of the germline itself (2018). He starts by asking how the germline should be understood *biologically*. As mentioned in *chapter 1*, the term *germline* is widely used, but is not altogether uncontested. Moreover, different definitions of the concept of *germline* are in circulation, of which the two most relevant are: 'a lineage of cells that continues through successive *generations* of individuals', and 'a lineage of cells within a *single individual*'[31] ("Germ line," n.d.-a; "Germ line," n.d.-b). Rehmann-Sutter criticises especially the first definition (which seems to be the mainstream usage of the term) and provides an alternative interpretation that could be seen as combining both definitions. In

[31] The online Oxford Dictionary defines germ line as "NOUN. *Biology.* A series of germ cells each descended or developed from earlier cells in the series, regarded as continuing through successive generations of an organism" ("Germ line," n.d.-a). The Merriam Webster dictionary provides two alternative definitions of germ line: "NOUN. The cellular lineage of a sexually-reproducing organism from which eggs and sperm are derived. *Also:* The genetic material contained in this cellular lineage which can be passed to the next generation" ("Germ line," n.d.-b). Therefore, in fact, there is a third interpretation of the concept of the germline, namely as heritable *genetic information* contained in the cellular lineage. I do not mention this in the main text as it would only complicate Rehmann-Sutter's discussion of the germline further.

this section I will discuss the different aspects of Rehmann-Sutter's proposed alternative biological understanding of the germline.

The germline understood as reaching through the body

According to Rehmann-Sutter, the germline is commonly (mis)understood as a *continuous lineage* of cells that connects the alternating order of zygotes[32] and germ cells[33] over generations (2018). He objects to this "essentialist reading of the germline as the bearer of a 'master genome' of the organism," (2018, p. 12) because it falsely depicts the bodies of individuals as offshoots from the germline. This fits in his larger critique on genetic determinism, and his objection to the understanding of DNA as the master molecule of life, as discussed in *chapter 3*. Rehmann-Sutter explains that during human embryonical development, germ cells are contained in the safety of the body and develop and mature there before giving rise to the next generation. Explained in more detail, differentiation (specialisation) of cells starts to occur only after the initial fertilised egg cells (the zygote) has undergone a number of cell divisions. Therefore, also the first precursors of the new germline cells only appear after approximately five cell divisions (i.e. after approximately six days of embryonic development). In line with this observation, Rehmann-Sutter proposes that the germline should be biologically understood as a specialised *part of the body* (like an organ). The germline is a lineage of cells that emerges from the developing embryo in every new generation, thus reaching *"through the body"* (emphasis original; 2018, p. 13).

Rehmann-Sutter further substantiates this by explaining that, as some of the early embryonic cells develop into the precursors of the germline cells, the *significant genetic information* (see *section 3.i*) contained within them changes, as a result of complex cellular processes, including epigenetic[34] reprogramming (2018). These processes are guided through interaction with other cells in the embryo, as well as by the molecular cues received from the pregnant mother's body. In other words, Rehmann-Sutter emphasises here the role of *bodily processes* in the development of the germline. Previewing his phenomenological discussion of the germline, I propose that we may speak of this process as affected by the *dual embodiment* (my phrase) of these cells: their containment within the embryonic body and the motherly body. According to Rehmann-

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[32] A *zygote* is a fertilised egg, the earliest stage of an embryo.
[33] Following Rehmann-Sutter (2018), I will use *germ cell* as equivalent to sperm of egg cell. This is normally (more appropriately) referred to as *gamete*.
[34] 'Epigenetics' refers to the pattern of heritable changes that are not strictly 'genetic' (i.e. not strictly relating to the DNA sequences of 'A's', 'T's', 'C's' and 'G's'). Epigenetic patterns include small molecular changes on the DNA (e.g. DNA methylation) as well as on the protein structure surrounding the DNA (e.g. histone modifications) and regulate the gene expression.

Sutter, this shows that the (genetic information contained in) the germline lineage is a *product* of the multicellular embryo, rather than the continuation of the unicellular zygote directly.

The germline and zygote understood as chicken-and-egg

In layman's terms, I propose that we may understand this part of Rehmann-Sutter's thesis on the germline as a variation on the classic chicken-and-egg dilemma. The succession of (egg)-chicken-egg- etc. is *not* linear and unchanging. Instead, an egg develops from the body of the adult chicken and is changed in the process. The successive generations of chicks are *embodied* by their emergence from the developing embryo in the egg as well as from the body of their chicken-mothers. Likewise, germ cells are specialised cell types that arise only through multiplication and differentiation of the initial fertilised egg (zygote). Therefore, the germline, which is the succession of (germ cell)-zygote-germ cell- etc., does not exist independent from the multicellular structure, the embryonic body, from which it derives. It does not make sense to view the germline as prior or superior to living individuals, because, like the chicken-and-egg, the germline emerges from the body, and the body emerges from the germline.

This description of the germline is in line with Rehmann-Sutter's idea of development as an *organic practice* as discussed in *section 3.i*: during development of the early embryo, the germline lineage emerges from complex cellular, environmental and bodily interactions, and this process takes place for its own merit, not for a higher end-goal (such as maintaining a germline through generations). Therefore, analogous to Rehmann-Sutter's writings on the ontology of development and DNA, I understand Rehmann-Sutter to mean that the germline is not *ontologically superior* to the (embryonic or adult) body (see row c of *table 1*, compare row a and b).

The germline understood as a vulnerable entity

In addition to arguing that we should let go of genetic essentialism in viewing the germline, Rehmann-Sutter draws a second conclusion from his biological description of the germline: the germline is vulnerable and does not reach unconditionally into the future (2018). This again is in line with his earlier writings on systems biology, where Rehmann-Sutter argued that developmental processes, the human body included, are fragile structures: if the equilibrium of the dynamic cellular processes is disturbed, development might wither or even halt (2002). Likewise, the germline is dependent for its continued existence on complex cellular interactions, and on the bodily environment of each new generation. If these processes are interrupted, there may be no next generation. The survival of the species is dependent on it. Therefore Rehmann-Sutter argues that the germline should be handled with care (2018). Combining Rehmann-Sutter's claim

that the germline reaches through the body, and that the germline is a vulnerable entity, emphasises that it is a line of cells that connects generations but that does not reach *unconditionally* into the future.

Rehmann-Sutter's biology of the germline forms the basis of his phenomenology of the germline, which is the topic of the next section. As we will see, the biological view on the germline is especially helpful to emphasise the role of the germline in the embodiment of generations from a phenomenological perspective.

ii. Rehmann-Sutter's phenomenology of the germline

The second part of Rehmann-Sutter's theoretical framework exists of an exploration of the phenomenology of the germline (2018). As the central questions of this exploration, Rehmann-Sutter asks, "How is knowledge about the germline given to us in experience?" (p. 14) In this section I will discuss how Rehmann-Sutter answers this question. As we will see, he does so mainly in terms of embodiment – through which it is interwoven with his biology of the germline – and relationships. The phenomenological perspective will form the basis for Rehmann-Sutter's argument of relationality with respect to germline editing, as we will see in the next chapter.

The germline understood as a corporeal intergenerational nexus

As we already saw in the former section, the germline has an explicitly bodily dimension. Taking a phenomenological perspective, Rehmann-Sutter goes on to argue that also in our *lifeworld*, the germline is part of our *embodiment*, even if (like the genome) we cannot perceive it directly through our senses (2018). Instead we obtain our knowledge about the germline indirectly, interpreting the meaning of inherited features according to our personal narrative. This knowledge about the germline interacts with our social relationships within the family and within society at large.

As we also saw in the former section, the germline is formed by the bodies of the individuals in each generation. In turn, the germline affects (albeit not fully prescribes) the appearance and functional capabilities of the bodies of the family members it brings forth. Rehmann-Sutter calls this the *generative* aspect of the germline (after his colleague Christina Schües, as will be discussed in *chapter 5*). In other words, the germline physically connects generations together. Through the lived experience, generations are also connected socially, through the relationships between family members. From the perspective of phenomenology, Rehmann-Sutter therefore argues that the germline should be also understood as the *embodiment* of these *intergenerational relationships*. In other words, the germline is a "*corporeal intergenerational nexus*": the bodily connection between generations (emphasis original 2018, p. 12). Indeed,

according to him, the germline is the most intimate and the most corporeal expression of the relationship between generations (2018, p. 14). Moreover, the germline "enables parenthood" and is therefore also *socially generative* (2018, p. 22).

Furthermore, according to Rehmann-Sutter, from the perspective of the lived experience, the germline connects generations within a family in two directions: forwards in time to the generations to come, and also backwards in time through our ancestry as well as from the child-to-be back to the parents. To understand what role the germline has in the lived experience, we should thus wonder what meaning is given to these *family relationships* in the lifeworld of an individual. This is where Rehmann-Sutter's thesis starts to become interesting for ethical questions raised by germline editing, as I will now discuss in the next section.

iii. Rehmann-Sutter's ethics of germline editing

Rehmann-Sutter uses his biology and phenomenology of the germline as a theoretical framework from which to address two moral questions regarding human germline editing (although he admits that other ethical questions could be posed too). The first relates to the level of safety required before germline editing could be considered, the second asks whether PGD (pre-implantation genetic diagnosis) or germline editing should be considered to be morally preferable. I will only address Rehmann-Sutter's discussion of the second question, because that is where he develops his argument of relationality.

In this section, I will first discuss how, according to Rehmann-Sutter, his ethics relate to his phenomenology. Then I will discuss his comparison between germline editing and PGD, with special attention to the idea of parent-child relationships. Next, I will formulate some critical notes on the validity of the moral conclusions that he draws and show why I do not agree. I will conclude that Rehmann-Sutter's biological and phenomenological perspective on the germline nevertheless remains fruitful for the attention that it draws to the argument of relationality, as I will explore in *chapter 5*.

Germline editing, relationships and responsibility: the argument of relationality

Rehmann-Sutter's discussion of the ethics of germline editing start from the remark that:

"[It is] in family and evolutionary intergenerational relationships reaching backward and forwards [in time] that germline alterations acquire moral significance. This is the context in which the ethical implications of [germline editing] must be understood and also evaluated." (Rehmann-Sutter, 2018, p. 15)

This shows that according to Rehmann-Sutter, his phenomenological perspective on the germline reveals an *ethical dimension* to germline editing, one that results from the significance of the germline to family relationships. Rehmann-Sutter does not explain why this would be so, but implicit in his remark are the assumptions that social relationships have moral significance in and of themselves, and that, as a result, anything that potentially disturbs these relationships should become the subject of moral inquiry. Therefore, also, the moral questions regarding the potential of germline editing are to be formulated in relation to their possible effect on intergenerational relationships. Relating to how these relationships should be characterised, Rehmann-Sutter goes on to say that:

"Family relationships are conceptualized as relationships of care and responsibility. … The ethical significance of practical knowledge about the germline, about its functioning, its fragility and about the possibilities of manipulating it, therefore need to be tackled in the context of these moral responsibilities and the inherent accountability of these relationships." (Rehmann-Sutter, 2018, p. 15)

In other words, these relationships should be characterised in terms of *responsibility*, *accountability* and *care*. While this is not the end-point of Rehmann-Sutter's argument (he proceeds by drawing a comparison with PGD, as I will discuss next), in my view, this is the core of what is interesting about his thesis on the germline: The *moral significance* of editing the germline of a child is embedded in the effect that it may have on *family relationships*. This is what I refer to as the *argument of relationality*. Exploring this further will be the topic of my next chapter. First, however, I will discuss the remainder of Rehmann-Sutter's article as it relates to parent-child relationships and parental responsibilities.

A comparison between germline editing and PGD

Rehmann-Sutter develops his account of the importance of intergenerational relationships further by drawing a comparison between germline editing and PGD (2018). He conceptualises this as a difference between *editing* and *selecting* embryos respectively, and asks which of the two would be morally preferable[35]. Rehmann-Sutter argues that PGD requires the selection of one of a limited set of possible future-persons[36]. In contrast, germline editing provides a plethora of choice regarding the possible genetic variants of the future child. According to Rehmann-Sutter, it is required that the parents are able to explain to their future child each possible choice in germline editing, including each possible choice *not to edit*.

[35] In posing this question, Rehmann-Sutter responds to the supposedly widely shared intuition that it is better to cure than to select, which would favour germline editing over PDG. I doubt however that it is indeed an intuition that is widely shared, and Rehmann-Sutter provides no source to prove that it would be so.
[36] Rehmann-Sutter does not refer to different 'persons' but rather to different 'mes' (plural of 'me' or 'I').

Rehmann-Sutter claims that, from the child's perspective, the choice to edit the embryo will be less readily understandable than the choice to select the embryo that had the least chance to be affected by a severe genetic disease. This is in part because the body (or the *embodied genome*) of the future child is affected by the editing choices made. Therefore, germline editing *co-creates* the genome of the person-to-be. In Rehmann-Sutter's admittedly dramatic words, "the genome will no longer be innocent" (p. 20). This negatively affects the parent-child relationship by making it more burdensome. According to Rehmann-Sutter, from the hypothetical perspective of the future child, this means that she might have an interest in not being edited. For the parents, it means that the *parental responsibilities* that they carry will change, in a manner that is unlikely to be favourable. Rehmann-Sutter concludes that PGD should be preferred over germline editing[37] (2018).

Two critical notes are in order. First, in his conclusion, Rehmann-Sutter provides a final judgement on the moral acceptability of germline editing but formulates it ambiguously. He writes: "I answer the question, 'Is [germline editing] justified?' with a No" (Rehmann-Sutter, 2018, p. 21). Taken literally, this seems to imply that Rehmann-Sutter holds that germline editing is *never* justified. However, later in his conclusion, he writes that we should act with caution in our handling of the germline, and that the decision to intervene in the germline should be thoroughly evaluated beforehand. This suggests that he does *not* categorically object to germline interventions after all, but that instead, he seems to mean that human germline gene editing cannot be justified *if PGD is an option*. This leaves unanswered the (perhaps more interesting) question whether and under what conditions to apply germline editing when PGD is *not* an option. This is a question that Rehmann-Sutter does not address.

More importantly, I question the plausibility of Rehmann-Sutter's claim that parents have the responsibility to explain to their future child the choice not-to-edit for every conceivable edit possible. I argue that this is unrealistic. If germline editing would become available to parents, the possible editing choices would be limited considerably by the technical limitations together with the regulative framework (resulting from societal and political forces) which would certainly be put in place. Remarkably, Rehmann-Sutter admits that the choice is "in part parental, in part technical, in part societal" (2018, pp. 19–20). Nevertheless, he

[37] It seems that Rehmann-Sutter thinks that there is a second reason why germline editing should not be preferred over PGD (2018). This is argument is however more complex, and not fully explicated by Rehmann-Sutter. In short, the argument goes that germline editing cannot be understood as a *cure* in the traditional sense, because the act that intends to cure the embryo, at the same time creates it. The implication seems to be that germline editing cannot *as a cure* be preferred over the act of selecting as performed by PGD (although Rehmann-Sutter does not explicate this second part of this argument). I leave this argument out in my discussion, because it does not aid our understanding of the argument of relationality.

seems to overlook the minimalizing effect that these preconditions will have on the scope of parental choice. The choice that will be left to the parents – and for which they will have to explain to their child when she grows up – becomes clearly demarcated by the restrictions of law and technology. Only a limited amount of options will remain. And it is only within this demarcation that we can realistically expect parents to explain to their child which editing and non-editing choices they made[38]. Indeed, in the near future, germline editing would conceivably only become available for severe (mono)genic diseases (see *chapter 1*), so that the choice 'to edit or not-to-edit' would be posed only to parents who carry such a disease, and the choice would then only apply to one edit (or potentially one 'package' of edits, in case of polygenic diseases), similar to what is currently the case for PGD. I propose therefore that the part of Rehmann-Sutter's argument that relates to the plethora of choice, could at best be reinterpreted as a plea to governing institutions to make sure that indeed the 'menu' of germline edits from which parents may choose remains limited.

It may be asked what this critique on the Rehmann-Sutter's comparison of PGD and germline editing means for the plausibility of his *argument from relationality*. I argue that, also if we accept this limited amount of choice as the most likely scenario, it might still be true that something about the relationship between parent and child might change if the germline of the child is edited. Compared to PGD, germline editing might not provide parents with *more choice*, but it might provide parents with choices for *new types of edits* (especially once the technology is established and possibilities outside the restricted 'severe monogenic disease' paradigm will be explored). Moreover, it might provide *more parents* with the possibility to edit the germline once the technology will become available for polygenic diseases (for which PGD provides no alternative). It could be speculated that, if usage of the technology would become established in society, the decision would be taken more lightly, and this would not benefit the parent-child relationships. And – perhaps most realistically – it might be true that even for the same kind of intervention (i.e. for the same disease) the choice to apply germline editing might still be *experienced* in a manner different from PGD. Intervening in the genetic structure of the child seems to be *intrusive* in a way selecting between embryos is not. Moreover, it might be experienced by the child and/or parents as expressing an (unpleasant) kind of *intentionality* (or – following Rehmann-Sutter's terminology - *creatorship*). If true, then it still seems plausible that the parent-child relationship might be burdened.

[38] I thank my supervisor Frans Brom for pointing out this fair argument in one of our first meetings.

iv. On the relation between the biology and phenomenology of the germline

In this section, I will shortly reflect on the relation between the different parts of Rehmann-Sutter's methodology, between the biology and phenomenology of the germline especially. Rehmann-Sutter asserts that "the background for discussing questions about the existential and social meanings of germline editing is biological knowledge." (Rehmann-Sutter, 2018, p. 12). This is realised most evidently in Rehmann-Sutter's emphasis on the germline as the *embodiment* between generations, which is a claim that relies on assumptions from biology as well as the lived experience. It is however not quite clear whether biology should be understood as being embedded in phenomenology, or that they are two separate approaches. In his article on the germline (2018), Rehmann-Sutter makes remarks in both directions[39].

The germline: five levels of meaning

This issue may be clarified by putting Rehmann-Sutter's thesis on the germline in the context of his earlier writings (Rehmann-Sutter, 2008; especially Rehmann-Sutter & Mahr, 2016) (see also *section 3.iii*). Analogous with the levels of meaning ascribed to *genetic tests* in *table 2*, I propose that we may discern five levels at which the *germline* can be meaningful to an individual also. From a biological perspective, the germline (level 2) arises only from the embryonic environment and the larger biological context of the mother's womb (level 1). In the other direction, we interact with the germline at a biomedical level, before and after the start of pregnancy (level 3). This may affect the manner in which the individual understands the germline as a part of her own body (level 4), and as connecting her to the bodies of her family members: her parents and her (potential) children (level 5). In his phenomenology of the germline, Rehmann-Sutter emphasises the role that the germline has in the relationship between generations, thereby emphasising the significance of level 5. See *table 3* for an overview of the five levels. In line with this description, I suggest that we should understand the biological and phenomenological as two separate but complementary perspectives on the germline, that inform each other, and both of which are part of the larger hermeneutic framework for understanding the concept of the germline.

[39] In his abstract, Rehmann-Sutter writes that he means to develop a theoretical framework for assessing ethical issues on the germline "based on an exploration of the phenomenology of the germline, from both biological and philosophical points of view" (Rehmann-Sutter, 2018, p. 9). However, in his main text, Rehmann-Sutter divides his theoretical framework in a biology of the germline, and a phenomenology of the germline, as two separate sections and ideas.

Table 3. *Five levels at which information about the germline can obtain meaning to an individual, ranging from biological meaning which is the topic of scientific studies, to experiential meaning, which is the topic of phenomenological studies. All levels may be subjected to hermeneutic investigations (table adapted from Rehmann-Sutter, 2008).*

biology		**lived experience**		
1	2	3	4	5
Epigenetic processes interacting with embryonic and motherly environment, generating germ cells	Germline, lineage of germ cells	Results of a pregnancy tests and check-ups and the possibility to intervene in the germline	Hermeneutic framework for understanding the biological significance of the germline as part of the body	Intergenerational relationships and family complexities regarding genetic (germline) relatedness

A critical note on the structure of Rehmann-Sutter's thesis

As said before, I wish to emphasise that the overall structure of Rehmann-Sutter's argument with regards to germline editing is not clear. This is proved for example by the range of (research) questions that he formulates in the course of his article. In reference to the supposed difference between germline editing (curing) and PGD (selection), the abstract open with the question: "Do we have a moral obligation to genetically cure embryos rather than selecting between them?" (2018, p. 9), and Rehmann-Sutter asserts that the aim of the article is to *critically evaluate* this question. In the introduction he formulates another question: "*Once [germline editing] is safe enough, why should it not be done?*" (emphasis original; p. 10). The conclusion starts with the remark that "We have tackled the question whether [germline editing] can be, in the best sense of the germ, a therapy." (p. 21) Rehmann-Sutter does however not directly formulate an answer to this question (although it seems that he considers the answer to be 'no'). In the same paragraph of the conclusion, he does answer another, even plainer question, "Is [germline editing] justified?", in the negative (p. 21). It seems in other words that even to Rehmann-Sutter himself, it is not clear what question he is trying to answer. Moreover, his thesis consists of several sections, and the relation between them is diffuse. At different points in his thesis (p. 9, 10, 11, 21, 22), Rehmann-Sutter explains the argument that he wishes to make, and the role that the several sections have in it, differently. As said, my discussion of his thesis in this chapter has aimed to highlight the most likely and most interesting parts of his thesis. To clarify this, in the next section I will recapitulate how I propose that his is work is best understood.

v. Rehmann-Sutter's thesis on the germline reconstructed

To finish up, I will reconstruct Rehmann-Sutter's thesis in the most plausible way by rephrasing it *in my own words*. In our moral thinking regarding genetic interventions in the human germline, there are two perspectives that we should take into account: how the genome and the germline could be understood from a scientific point of view, and what meaning is ascribed to the idea of the genome and the germline in everyday life. Both perspectives matter most in relation to inheritable genetic diseases, as these will form the context in which germline editing is most likely to be considered, at least at first.

Scientifically speaking, we should let go of the almost metaphysical importance that we ascribe to the genome. We are not our genes. The sequence of our DNA is only one aspect of what determines human embryonic development. Likewise, we should not understand the germline as a cellular entity that connects generations together independent of the individuals it brings forth. The germline exists as a cellular lineage within each individual. To the extent that a germline also exists as a lineage that connects generations, it is the individuals of each generation that make up that germline, not the other way around.

From the perspective of phenomenology, the idea of the germline symbolises kinship and genetic relatedness. The germline physically relates one generation to the next: It is the physical presence of the germ cells that melt together to form a zygote which develops into the body of a new person, the genetically and physically related child. It generates a new body out of two adult bodies, and therefore the germline is the embodiment of family relationships. This embodied connectedness reaches back into the past and forward into the future, but in different ways. We can trace our inheritance back through the generations that have already been, as a stable given. But we cannot extrapolate it into the future unconditionally. The germline is a fragile entity that may or may not give rise to a next generation. In the lived experience of individuals, parental responsibilities and intergenerational relationships flow from the genetic relatedness and vulnerability that the germline represents. In that sense, the germline does not only biologically, but also morally connect generations together.

Finally then, these perspectives should guide our reflection on ethical questions that arise regarding directed interventions in the genome of human embryos using CRISPR-Cas9 technology. There is something explicitly intentional in the use of this technology compared to other reproductive technologies (PGD specifically), and this is mainly due to its ability to change the genetic structure of the embryo that will develop into a child. It is not the plethora of choice, but rather this intentionality expressed in such a precise edit, as well as the intrusiveness of interrupting in the germline, that might be bothering. This may have

implications for the parent-child relationships that are fostered during childhood, and this may change the responsibilities that the parents carry.

The suggestion that one should aim to understand the implications that germline editing will have for the parent-child relationship and for parental responsibilities (i.e. the argument of relationality) seems promising. Unfortunately, Rehmann-Sutter has trouble formulating concretely what the change in these responsibilities signifies[40]. Therefore, in the remainder of this thesis, I will explore how the concepts of intergenerational relationships and parental responsibilities could be understood in the light of germline editing. To this end, I will draw on the work some of the authors on whom Rehmann-Sutter's thesis is based. In doing so, I will aim to suggest how Rehmann-Sutter's phenomenological approach could become more useful to guiding practical responses to moral issues raised by germline editing.

[40] As an example of this obscurity, consider the following unexplained remark from Rehmann-Sutter, which he poses in the context of intergenerational relationships: "Insofar as choice and agency are involved, responsibilities and liabilities are emerging." (2018, p.22)

Ch 5: Intergenerational relationships and parental responsibilities

As we have seen in the chapter 2 & 4, Rehmann-Sutter's theoretical framework on the germline and the argument of relationality that he draws from it, could be of added value to the mainstream bioethical discourse on germline editing. This is because he brings afore the importance of considering what effects germline interventions may have on intergenerational relationships and the responsibilities that parents carry. It may form the starting point towards filling one of the gaps that are left open in this discourse, namely the contextual perspective of the parents and the children and the effect that the practice of editing may have on their family and personal lives. It allows to give merit to the significance of family relationships. Rehmann-Sutter himself, in his recent publication, has however not substantiated the meaning of these relationships in a very concrete manner, nor does he provide suggestions as to what the effects of germline editing on family relationships may be. Rehmann-Sutter provides only a few cues in this direction, namely, that the parent-child relationship should be understood as an *intergenerational* and *generative* relationship and that it should be conceptualised in terms of *care* and *responsibility* (2018, p. 14,15). Therefore, in this chapter I will pick up on these cues in order to develop Rehmann-Sutter's argument of relationality further, so that it might form a fresh impulse to the mainstream ethical debate.

This chapter will be divided in three sections. In the first section (*5.i*), I will expand on the idea of *intergenerational and generative relationships* based on the two scholars to whom Rehmann-Sutter refers. This brings us on a path that leads along childhood studies, the sociology of childhood and feminist phenomenology. In the second section (*5.ii*), I will discuss *responsibility* as the ethical dimension of relationships, by looking at how it is conceptualised in the *ethics of care*. In the third section (*5.ii*), I will establish a notion of *parental responsibility* and argue that constructing the narrative of their decision-making process will (in part) help parents to fulfil this responsibility.

i. Childhood studies and intergenerational relationships

Rehmann-Sutter repeatedly speaks of *intergenerational relationships* and seems to borrow the concept from two authors, Leena Alanen and Christina Schües (Rehmann-Sutter, 2018, p. 15). Alanen discusses intergenerationality in the context of the sociology of childhood. Schües develops an idea of generativity from a feminist phenomenological approach that is not dissimilar to that of Rehmann-Sutter. Moreover, together with Rehmann-Sutter, she has published on the meaning that generative relationships have for

childhood wellbeing. I will discuss each of these points below, in order to give body to Rehmann-Sutter's understanding of intergenerational relationships.

Alanen: Childhood and intergenerationality

Alanen explores the concept of *intergenerationality* from the viewpoint of the sociology of childhood[41] (2014). She notes that childhood is not merely a stage in the development towards adulthood, but that children also have social agency of themselves (Alanen, 2014, p. 134). This fits well in Rehmann-Sutter's *poiesis/praxis* distinction, emphasising that childhood is a developmental stage valuable of its own. She then conceptualises intergenerationality as the relationship between children and adults understood as members of a *social* generation (*see footnote 10*). Intergenerationality, however, may also describe the relationships within the nuclear family. She argues that the family is often idealised as a place of emotional closeness and trust, and in order to be maintained, the family feeling of love and affection between all family members must continuously be (re)created. Within this family, intergenerational relationships connect family members together, and lend each family member her identity and position within the family, in an interdependent manner. According to Alanen, while the relationship need not be symmetrical (in fact, it is often asymmetrical), this *interdependency* or reciprocity is essential (but not often acknowledged) in the relationship between parent and child. To reflect this flow in two directions, the act of *childing* could be coined as a counterbalance to *parenting* (2014). Rehmann-Sutter reflects this reciprocity in his description of the intergenerational relationship as reaching backwards and forwards in time.

Schües: Bio-phenomenology and generative relationships

Rehmann-Sutter borrows the idea that the intergenerational relationship is a *generative* relationship from his colleague and co-author Schües. She has explored elaborately the phenomena of natality and generativity, and the meaning of "being born by somebody, with somebody" (Rehmann-Sutter, 2018, p. 15; Schües, 2017, p. 223). Like Rehmann-Sutter, Schües has suggested that reproductive and genetic technologies may change something fundamental about intergenerational relationships (Schües, 2017, p. 224). And like him, she employs a hermeneutic phenomenology to address questions in the field of biotechnology and bioethics. According to Schües, the meaning of life is embedded in experiences, specifically, experiences with others. Our embodied existence is a prerequisite of these relational experiences. Therefore, intimate technologies that intervene in our bodies (like germline editing) also

[41] Remarkably, Alanen is explicitly concerned with childhood as a *structural* rather than a *phenomenological* concept. It is therefore curious that Rehmann-Sutter chooses to refer to this author.

change our relationships and the meaning that we give to our lives. Schües' approach, which she dubs *bio-phenomenology*, is aimed at helping to understand such developments. To draw attention to considerations of relationality, Schües especially advocates a *feminist* take on phenomenology. She favours feminist ethics over mainstream forms of ethics, because it is less individualistic and acknowledges the need for sensitivity to context and narratives (Schües, 2017).

As we saw, Schües explains parent-child relationships as generative (*section 4.ii*). The concept of *generativity* is set out more elaborately in an article on child wellbeing that she co-authored with Rehmann-Sutter (Schües & Rehmann-Sutter, 2013). They explain generativity as having several meanings at once. It is about becoming: becoming a person in this world, and becoming a child in a family. It is about the socio-historical as well as biological and *bodily* connection between generations. This explains Rehmann-Sutter's assertion that the germline is a generative entity.

According to the Schües and Rehmann-Sutter, relationships with others are what gives meaning to a human life and therefore matters to wellbeing. The authors define *generative relationships* as "familial relationships across generations that are constituted through birth, parenting, and education" (Schües & Rehmann-Sutter, 2013, p. 199). Generative relationships, therefore, are necessarily also intergenerational relationships. The quality of generative relationships matters specifically to a child, because she is born into them and cannot choose them. The authors suggest that good quality family relationships are relationships of trust, support, intimacy and care. More broadly, for a child, "wellbeing … is embedded in a relational structure of intentions and feelings, values, and norms." (2013, p. 200) Importantly, the authors note that for the wellbeing of a child, also the narratives that the parents use in their relationship with her matter, especially when it is contested what decision would promote her interest best. Narrative construction can guide ethical decision-making in the family context and can help bridge the gap between the description of a situation and moral judgement, especially in the context of (generative) relationships. I will embroider upon this point in *section 5.iii* of this chapter.

Last, remarkably, the authors remark that a child's development "is always about the future" [42]. This implies that parents have to take responsibility for the impact of their decisions on the future wellbeing of the child as she will finally grow into an adult (Schües & Rehmann-Sutter, 2013, p. 204).

[42] Note that this seems to contradict Rehmann-Sutter's earlier discussion of organic development as a praxis (2006), which implied that development is also (or even mainly) about the present.

Insights on childhood relationships

Overall, I propose that we may take the following valuable insights from the afore discussion of relationships and relationality as they are conceptualised in the sociological and phenomenological childhood studies of Alanen and Schües. Both authors emphasise that relationships are central to our experiences and our wellbeing, and so that we should regard human beings, not as isolated individuals, but as related to others and embedded in a social context. For parents and children, this social context is the family, and their relationship is a relationship between generations. Family relationships are especially important for the wellbeing of a child, because she is born into them and depends on them. In the ideal situation, childhood relationships express trust, affection and care, flowing in two directions: from the parent to the child, and from the child to the parent. The relationship therefore is reciprocal, and is marked by interdependency, even if the child and parent depend on each other in different ways. Parenting decisions should be guided not only by rational thinking, but also by empathy and affection. In these decisions, parents should respect both the child in itself as well as the adult into whom she will grow up, and narrative construction can help to guide this process.

The merit of this discussion to Rehmann-Sutter's hypothesis that germline editing might change the parent-child relationship is two-fold: First, it highlights the importance of family relationships to the wellbeing of the child, and therefore sustains the claim that burdening the relationship is indeed undesirable. Second, it shows that what it is that should be maintained is trust, affection and reciprocity in family relationships.

ii. Care ethics and relationality

To bridge the gap between (inter)generational relationships and normative questions on germline editing, the moral dimensions of these relationships needs to be brought out. More than once, Rehmann-Sutter refers to the *ethics of relationships* (Rehmann-Sutter, 2006, p. 332, 2018, p. 25; Schües & Rehmann-Sutter, 2013, p. 203). This does not (yet) seem to be an established field of inquiry. Therefore, to conceptualise the ethical dimension of relationships, I take my cue from *care ethics* instead. I will draw on the description given by the prominent care ethicist Eva Kittay (to whom Rehmann-Sutter refers 2018, p. 15; Sander-Staudt, n.d.), and on the work of his colleague Jackie Scully[43], who has related care ethics to genetic technologies. I will now discuss each of them in this section.

[43] Note that Scully is also one of the members of the working party of the Nuffield Council that composed their most recent report on germline editing (2018).

Kittay: Care ethics and dependency relationships

According to Kittay, at its core, *care ethics* is about relationships, the *responsibilities* that flow from that and the possibility of care (2006). In care ethics, each moral agent is seen as essentially related to other selves, rather than seen as an isolated, independent and autonomous being. The scope of care ethics is explicitly not universal, but rather promotes partiality towards those to whom we are in relational (and geographical) closeness. It can therefore be understood as opposite to universalist ethical theories such as consequentialism or deontology.

Care ethics recognises the contingency of our place in the world and our relationships with other, as well as the power differences and differing capacities within these relationships. Relationships of care tend to be *dependency relationships*. The most vulnerable or dependent one in the relationship may however not become a victim of the relationship, but should be treated with respect. These relationships should be affiliative in kind, and fostering such relationships should therefore be acknowledged as an expression of human connectiveness and human flourishing. In these relationships, and in our actions, we should be primarily responsive to the needs of others, instead of to our own, so that moral deliberation becomes a process of empathy and emotional responsiveness towards the narrative of another's situation and needs. *Responsibility* and *responsiveness* are then the central units of morality (Kittay, 2006).

Scully: Care ethics and embodiment

Scully discusses care ethics in the context of disability and reproductive technologies (Scully, 2006). Like Alanen and Kittay, Scully suggests that our moral bonds derive from our interdependency with others, and that these moral relationships are often *asymmetrical*. Scully proposes that care ethics is especially well suited to account for such asymmetry, because it ascribes importance to relationships and the perspective of the agents at each side of the relationship. According to her, the great merit of care ethics is that it helps us understand that every person as a moral agent has her own position in this world, that will never be entirely the same as our own. Interestingly, at this point she notes: "What is just needs to be perceived not by me putting myself into your shoes, but by me trying to understand how you, in your shoes, might perceive things – and accepting that I am and always will be limited in my attempts." (Scully, 2006, p. 251) She argues that our situatedness in the world is integral to our experiences and perceptions, and that, therefore, it also affects our moral thinking and ethical judgements. She pays special attention to our embodiment, including (dis)abled embodiment, as part of this situatedness and holds that we should try to understand the social and embodied context of another before judging her actions. She objects to new reproductive technologies to the extend that they threaten the embodied lifeworld the disabled.

Insights on the ethical dimension of relationships

Overall, care ethics is valuable because it recognises that the importance of the relational aspect of our existence to our moral actions, and it conceptualises the *ethical* dimension of these relationships as *responsibilities*. It requires us try to comprehend the need of others from the perspective of their lifeworld and to be responsive to that. It draws attention to relationality, contextuality, situatedness and embodiment. Applied to Rehmann-Sutter's argument of relationality in germline editing, it suggests that the ethics of the parent-child relationship should be regarded in terms of *parental responsibility*, as Rehmann-Sutter has suggested himself as well (2018). Parents should not only take into account their own lifeworld, but also the perspective of the embodiment of their (future) child and should be responsive to her needs. What this may practically mean for germline editing decisions will be the topic of the next section.

iii. Parental responsibilities in germline editing decisions

Rehmann-Sutter has argued that what is morally troublesome about germline editing is that it might burden the parent-child relationship and change the responsibilities of that the parents carry. Care ethics confirms we should be concerned with responsibilities as the normative component of relationships. Their responsibility is at least in part related to the decision of whether to opt for germline editing. After all, when opting for germline editing, the parents are the ones who initiate the request for the germline intervention procedure, and the ones to whom the final decision to proceed befalls. Therefore, even if the parents are not the only agents involved in the decision-making process (the medical staff and indirectly policymakers also play a role), they do cary responsibility for the final decision that is made. Rehmann-Sutter has argued that, when deciding to opt for germline editing, parents have to be able to explain this choice to their child convincingly. Parental responsibility in germline editing is therefore at least partly expressed in their need to explain and account for this decision. In this section I will expand on this idea by first proposing how parental responsibilities in germline editing may be conceptualised in a general sense, and then speculating on what the need for explanation may mean for the parents in a practical sense. In this discussion, I will draw on the insights on intergenerational relationships and their ethical dimension, as provided in the former two sections.

Parental responsibilities in germline editing decisions conceptualised

Understanding the characteristics of parental responsibilities would be helpful to explicate their role in germline editing. As discussed, in care ethics, responsibilities are considered to be the central unit of morality

and are conceptualised in terms of responsiveness to the needs of others[44] (Kittay, 2006). Based on the earlier discussions in this chapter, I propose that in the context of germline editing, parental responsibilities may be characterised as having at least the following four assets. Firstly, these responsibilities are *family responsibilities*. Kinship, the fact of being related (genetically or socially) as family members seems to put certain obligations on people. Secondly, they are *parental responsibilities*, accorded to one in the role of being the parent of one's child. Thirdly, they are responsibilities of adult persons towards young persons, i.e. towards *children* in a different sense of the word. As they are in the early stages of their development, children are vulnerable and dependent beings, and therefore the responsibilities are also *responsibilities towards the vulnerable*. Lastly, they are *responsibilities towards future persons* specifically. This means that, as far as they flow from relationships, they are responsibilities in light of the relationship that the parents will have with their child *in the future*. This is because, at the moment of decision-making (to edit or not-to-edit), the child does not yet exist. At that point, the responsibilities flow in one direction only: from the prospective parents towards the future child. Reciprocity in the relationship will occur only by the time the child grows up. This adds a second layer of dependency to the parent-child relationship. From the perspective of an ethics of care, the responsibility to respond to the needs of the child and to provide care and affiliation, follows from this dependency relationship as well as from the family relationship between parent and child.

Germline editing and decision-making narratives

Last, I will propose one of the practical implications of these responsibilities of prospective parents towards their future children when making germline editing decisions. Rehmann-Sutter argues that, when opting for germline editing, parents will need to be able to explain their decision-making process to their future child when she grows up (2018). This implies that, naturally, it is required that the decision is well thought through. Therefore, I argue that the parents themselves should be stimulated to go through a process of moral reflection. Moreover, parents should be aware of the reciprocity and dependency in their (future) relationship with their child, and, as Schües has pointed out, in this the narrativity of their decision-making processes matters. Together, I propose that, regarding the decision to opt for germline editing, this points

[44] Other than that, the discussion of relationships in the current chapter has told us surprisingly little on the topic of *responsibilities* directly. Rehmann-Sutter (2018) refers to only one other author who has studied responsibilities: Janet Finch. The work he cites however explicitly discusses responsibilities in kinship relationships of among adults and is therefore not quite applicable to the question of what responsibilities parents carry with respect to their future children.

to a need for the parents to (re)construct the narrative of their decision-making process and the decision that it brought about.

Such a narrative construction will allow the parents to explore their considerations and their own context, and to (re)construct the reasons for their decisions in a helpful way. In this narrative, the parents should try to understand their own decision in the context of their own life history, their embodiment and their family situation and should reflect on their wish for a genetically related child. The narrative should also include the perspective of the (potential) other parent involved in the decision-making process, which is a hermeneutic activity. And importantly, it should take into account the imagined narrative of their future child. The parents should try to imagine how their child might explain her own coming into being when she grows up, and what the effect of germline editing might be on the experience of her own embodiment. The parents should reflect on how their choice might affect the way they will relate to their child, and the way their child will relate to them. They should acknowledge the importance of this relationships to their child's (and their own) wellbeing and acknowledge the reciprocity and dependency in the relationship. To this end, narrative construction requires an *emphatic* as well as an *imaginative* attitude.

Overall, I argue that constructing the narrative of their decision-making process may help the parents to gain confidence in the quality of their decision to request a germline intervention, before the final decision to proceed is made. If the parents do not succeed in constructing a narrative that they consider sufficiently forceful to imagine explaining the decision to their future child, they may choose to abstain from the intervention instead. Furthermore, such narrative construction will prepare for the explanation that the parents will have to give to their child when she will have reached a suitable age. It will help the parents to be able to make a choice that derives from good and loving intentions, so that they will be able to explain their choice as an expression of their love for their future child. This narrative therefore will have an explanatory and as well as a reflexive function.

Conclusion and discussion

In conclusion, in this thesis, I have aimed to show that Rehmann-Sutter's biology and phenomenology of the germline and the argument of relationality that he draws from it are a valuable addition to the bioethical discourse on germline editing. Rehmann-Sutter has argued that what is morally troublesome about germline editing is that it might change the relationship between parent and child. This argument of relationality draws attention to the lifeworld of the persons who will be most directly involved in germline editing decisions, namely the child and her parents. This is needed because the mainstream debate tends to overlook this perspective and does not recognise the role that the parent-child relationship will have in how interventions in the germline will be experienced.

The argument of relationality recapitulated

Rehmann-Sutter's argument of relationality is based on a theoretical framework which serves to understand how the concept of the germline itself should be understood. This framework incorporates both a biological and a phenomenological perspective on the germline. From a scientific biological perspective, the germline is understood as a cellular lineage that arises from the body of every new generation. It is a vulnerable entity that reaches *through* their bodies. From a phenomenological perspective, which considers the meaning ascribed to the germline through the lived experience of individuals, the germline is understood as the embodiment of the relationship between generations, between parent and child. It connects them physically backwards and forwards in time. Together, Rehmann-Sutter has depicted the germline as an intergenerational corporeal nexus. In the lifeworld, this nexus gains meaning as the expression of family relationships.

Rehmann-Sutter has used this theoretical framework to understand how interference in the germline may be experienced. Because the germline is an expression of the relationship between parent and child, interfering in the germline by means of CRISPR-Cas might complicate this relationship. According to Rehmann-Sutter, this is because germline editing would provide a plethora of choice. I have rejected this last part of Rehmann-Sutter's argument and argued that, instead, the parent-child relationship might be complicated because there is something explicitly intentional in changing the genetic structure of a human germ, potentially more so than in other reproductive technologies like PGD.

Last, we have seen that good quality relationships matter because they form an important part of our human existence and the meaning we give to our lives. For the wellbeing of a child, family relationships are especially important because she is born into them and is dependent on them. Therefore, the decision to

opt for germline editing should be an expression of parental love and should allow for a parent-child relationship characterised by reciprocity, trust and affection. It is therefore of utmost importance that the parents reflect carefully on the effect that germline editing may have on their relationship with their child. To foster such a reflective attitude, parents should construct the narrative of their decision-making process, taking into account the perspective of their own lifeworld and the imagined embodiment of the future child. At the same time, such narrative construction could help the parents to take responsibility for their choice and to be able to explain it to their future child in a satisfactory manner. This would allow for a relationship of care, trust and affection between the parent and child even when germline editing is opted for.

A valuable addition to bioethical discourse

The argument of relationality may form a valuable addition to the mainstream bioethical discourse. This discourse is dominated by arguments of safety, benefits, autonomy and justice and too little attention has been paid the perspective of the parents and children related through their intergenerational family relationship. In particular, the argument of relationality may serve to counterbalance, or at least nuance, the dominant talk of parental autonomy. It emphasises that, while parents should be allowed freedom to make reproductive choices themselves, they make this choice not independently, but in a social context, in relation to each other, and importantly, also in relation to their future child. This argument can be taken as a philosophical argument to inform the debate amongst bioethicists. In addition, it could be taken as a practical argument to inform policy decisions, where merit should be given to the fact that parental decision-making should be more than an expression of reproductive autonomy, but one in which the parent relates to her imagined child.

It may now be evaluated in what sense Rehmann-Sutter's argument of relationality is truly novel and be remarked that a parallel is to be found between his argument and that of Sandel specifically. Sandel has argued that parental attempts to enhance the abilities of their child are objectionable for several reasons, one of which is that it would leave less to chance and more to choice, and therefore would expand the breadth of parental responsibilities. This idea seems to be echoed in Rehmann-Sutter's remark that parental responsibilities might change, especially because they would lead to an immense amount of editing choices (an argument that I have partly rejected). Rehmann-Sutter's argument is however different from Sandel's for several reasons. First, it is applied to therapeutic (rather than enhancing) parenting choices. Second, it is applied to germline editing specifically, not to any parental decision-making. Third and most importantly, Rehmann-Sutter approaches this question from the perspective of the lifeworld of the individuals

concerned, while Sandel rather analyses tendencies in society at large. This provides Rehmann-Sutter with the advantage that he can base his argument on a concern for the persons who will be most directly affected by parenting decision, and therefore provides a depth that – in my view – Sandel's argument lacks.

Future research

Last, it may be noted that – taking into account my discussion of Rehmann-Sutter's methodology in *chapter 3*, especially his hermeneutic phenomenological approach to empirical research – it makes sense to understand this argument that germline editing may change the parent-child relationship as a *hypothesis* that is in need of further empirical research. Drawing on Rehmann-Sutter's biologically informed hermeneutic phenomenology, and on insights from childhood studies and care ethics, in this thesis I have tried to show why good quality relationships between a child and her parents would matter. However, asking how germline editing might truly affect these relationships and what implications this may have for the wellbeing of the child is an empirical question. To understand the perspective of parent and child more thoroughly, I propose that qualitative empirical studies should be performed. These studies should serve as a means to approach the perspective of parent and child, and to clarify what responsibilities might be ascribed to the parents in the context of their real lifeworld. Such studies should also help to clarify whether germline editing will indeed be essentially different from other reproductive technologies. I will finish this thesis with some suggestions as to what further research ought to be performed to substantiate Rehmann-Sutter's argument of relationality.

Phenomenology as a forward-looking endeavour

I propose that the qualitative empirical approach based in phenomenology and hermeneutics that has been proposed by Rehmann-Sutter (see *section 3.ii*) is suitable to explore how germline editing may be experienced in the real lifeworld of the actors who will be involved. There is however a major challenge to be found in that germline editing is still hypothetical and cannot be studied directly. To apply phenomenology in a forward-looking manner, I propose that an analysis could be performed of related technologies that are already in place as a proxy for the future technology of germline editing. Furthermore, the lifeworld of the potential users and their attitudes towards the technology might be analysed.

I propose to start with literature review. Quite a large amount of qualitative empirical research is already available on how existing reproductive and genetic technologies are being perceived by parents and medical practitioners (e.g. see Leefmann, Schaper, & Schicktanz, 2017). Many of these studies are concerned with (pre- and post-conception) genetic testing technologies specifically. A number of such studies also use interpretative phenomenological analysis (IPA) as a research method and are therefore roughly compatible

with Rehmann-Sutter's methodology. Complemented by Rehmann-Sutter's own prior studies into such topics, a literature review of these studies might serve as a base from which to figure out what is already known about how genetic relatedness, the genome, genetic diseases and the germline are conceptualised in everyday life. Additionally, studies into the perceptions of children who have been born through reproductive technologies, especially through PGD, may be included (e.g. Indekeu & Hens, 2019). Such studies are rare but of great interest, as they may be used as an initial examination of Rehmann-Sutter's hypothesis that reproductive technologies (as a proxy for germline editing) affect the relationships between parent and child in a negative way.

A proposal for qualitative empirical research

Based on the outcomes of this literature review, a research agenda for (phenomenological) qualitative empirical research might then be developed. Anticipating the outcomes of the literature review, I propose three research directions to gain insight into (if and) how germline editing will affect parent-child relationships.

Firstly, qualitative interviews may be performed with children who have been born through reproductive technologies such as PGD, and with their parents (and potentially other family members). Such research might ask: What narrative do the parents tell on hindsight about their decision-making process? What narratives do the parents and the children construct about their family relationships and the potential role that the reproductive technology has in that? What narrative does the child tell about her own life history and self-conception, and what place (if any) is given to the reproductive interventions in that? Such research will help to understand how family relationships and parental responsibilities are conceptualised by the parents and children who find themselves in the relevant situation.

Secondly, studies might be performed into the attitudes of persons who are affected by (or carrier of) severe inheritable diseases of the type that might be prevented by the use of germline editing. This group has a three-fold representative function: it represents the children-who-would-not-be-born when germline editing is carried out, it includes potential users of the technology (i.e. prospective parents wishing for a genetically related healthy child), and it represents the group that might be stigmatised or discriminated against when germline editing becomes allowed. Learning about the attitudes towards the disease from the perspective of their embodiment will help to foresee what the impact of the actual germline intervention on their lifeworld may be.

Thirdly, qualitative research could be done amongst a broader group of participants to explore what role the germline plays in the lifeworld of people in everyday life, and to find out what value is given to genetic

relatedness amongst (genetically related and non-genetically related) family members. This may shed light on the assumption that underlies any potential decision to opt for germline editing, namely that it is valuable to conceive a child who is genetically one's own. It will also help to examine Rehmann-Sutter's hypothesis that the germline is valued as the physical entity that relates generations backwards and forwards in time.

Once such studies are available, phenomenological philosophical reflections on the outcomes of these studies might be used to help to try to foresee what the effect of germline editing on the relationships will be.

A loving parent-child relationship

Overall, the main value of Rehmann-Sutter's combined biological and phenomenological approach for answering questions regarding the germline is the emphasis it puts on the need to consider the lived experience of parent and child. It may be hypothesised that interfering in the genetic structure of a child will change something fundamental in her relationship with her parents. This parent-child relationship bears responsibilities within it, importantly the responsibility for parents to make a choice in which, foreseeably, the child is able to understand herself in a loving relationship with her parents.

Literature

Alanen, L. (2014). Childhood and intergenerationality: Toward an intergenerational perspective on child well-being. In *Handbook of Child Well-Being: Theories, Methods and Policies in Global Perspective* (pp. 131–160). Dordrecht: Springer. https://doi.org/10.1007/978-90-481-9063-8_5

Baltimore, D., Berg, P., Botchan, M., Carroll, D., Charo, R. A., Church, G., … Yamamoto, K. R. (2015). A prudent path forward for genomic engineering and germline gene modification. *Science*, *348*(6230), 36–38. https://doi.org/10.1126/science.aab1028

Beauchamp, T. L., & Childress, J. F. (2009). *Principles of Biomedical Ethics* (7th ed.). Oxford: Oxford University Press. https://doi.org/10.1016/B978-0-12-800034-2.00245-7

Bosley, K. S., Botchan, M., Bredenoord, A. L., Carroll, D., Charo, R. A., Charpentier, E., … Zhou, Q. (2015). CRISPR germline engineering - The community speaks. *Nature Biotechnology*, *33*(5), 478–486. https://doi.org/10.1038/nbt.3227

Bredenoord, A. L., Dondorp, W., Pennings, G., & De Wert, G. (2011). Ethics of modifying the mitochondrial genome. *Journal of Medical Ethics*, *37*(2), 97–100. https://doi.org/10.1136/jme.2010.037481

Carel, H. (2011). Phenomenology and its application in medicine. *Theoretical Medicine and Bioethics*, *32*(1), 33–46. https://doi.org/10.1007/s11017-010-9161-x

Cavaliere, G. (2018). Genome editing and assisted reproduction: curing embryos, society or prospective parents? *Medicine, Health Care, and Philosophy*, *21*(2), 215. https://doi.org/10.1007/S11019-017-9793-Y

Chapman, E., & Smith, J. A. (2002). Interpretative phenomenological analysis and the new genetics. *Journal of Health Psychology*, *7*(2), 125–130. https://doi.org/10.1177/1359105302007002397

Christoph Rehmann-Sutter. (n.d.). In *Wikipedia*. Retrieved from https://en.wikipedia.org/wiki/Christoph_Rehmann-Sutter

COGEM, & Gezondheidsraad. (2017). *Ingrijpen in het DNA van de mens- morele en maatschappelijke impicaties van kiembaanmodificatie*. Bilthoven: Commissie Genetische Modificatie (COGEM). Retrieved from https://www.gezondheidsraad.nl/documenten/adviezen/2017/03/28/ingrijpen-in-het-dna-van-de-mens

Cyranoski, D., & Ledford, H. (2018, November 26). Genome-edited baby claim provokes international outcry. *Nature News*. Retrieved from https://www.nature.com/articles/d41586-018-07545-0

Doudna, J. (2015). Perspective: Embryo editing needs scrutiny. *Nature*, *528*(7580), S6–S6. https://doi.org/10.1038/528S6a

Doudna, J., & Charpentier, E. (2014). The new frontier of genome engineering with CRISPR-Cas9. *Science*, *346*(6213). https://doi.org/10.1126/science.1258096

Düwell, M. (2012). Nature and life. In *Bioethics: Methods, Theories, Domains* (pp. 125–140). London: Routledge.

Dzau, V. J., McNutt, M., & Bai, C. (2018). Wake-up call from Hong Kong. *Science*, *362*(6420), 1215–1215. https://doi.org/10.1126/science.aaw3127

Gallagher, S. (2012). Introduction: The Situation of Phenomenology. In *Phenomenology* (pp. 1–6). Basingstoke: Palgrave Macmillan.

Germ line. (n.d.-a). In *English Oxford Dictionaries Online*. Retrieved from https://en.oxforddictionaries.com/definition/germ_line

Germ line. (n.d.-b). In *Merriam-Webster Dictionary Online*. Retrieved from https://www.merriam-webster.com/dictionary/germ line

Gyngell, C., Douglas, T., & Savulescu, J. (2017). The Ethics of Germline Gene Editing. *Journal of Applied Philosophy*, *34*(4), 498–513. https://doi.org/10.1111/japp.12249

Harris, J. (2015). Germline Manipulation and Our Future Worlds. *American Journal of Bioethics*, *15*(12), 30–34. https://doi.org/10.1080/15265161.2015.1104163

Indekeu, A., & Hens, K. (2019). Part of my story. The meaning and experiences of genes and genetics for sperm donor-conceived offspring. *New Genetics and Society*, *38*(1), 18–37. https://doi.org/10.1080/14636778.2018.1549476

Jinek, M., Chylinski, K., Fonfara, I., Hauer, M., & Doudna, J. A. (2012). A Programmable Dual-RNA – Guided DNA Endonuclease in Adaptive Bacterial Immunity. *Science*, (June), 1225829. https://doi.org/10.1126/science.1225829

Kittay, E. F. (2006). The Concept of Care Ethics in Biomedicine. The Case of Disability. In C. Rehmann-Sutter, M. Düwell, & D. Mieth (Eds.), *Bioethics in Cultural Contexts* (pp. 319–339). Dordrecht: Springer. https://doi.org/10.1007/1-4020-4241-8_21

Lander, E. S., Baylis, F., Zhang, F., Charpentier, E., Berg, P., Bourgain, C., … Winnacker, E. L. (2019). Adopt a moratorium on heritable genome editing. *Nature*, *567*(7747), 165–168. https://doi.org/10.1038/d41586-019-00726-5

Lanphier, E., Urnov, F., Haecker, S. E., Werner, M., & Smolenski, J. (2015). Don't edit the human germ line. *Nature*, *519*(7544), 410–411. https://doi.org/10.1038/519410a

Leefmann, J., Schaper, M., & Schicktanz, S. (2017). The Concept of "Genetic Responsibility" and Its Meanings: A Systematic Review of Qualitative Medical Sociology Literature. *Frontiers in Sociology*, *1*,

18. https://doi.org/10.3389/fsoc.2016.00018

Mantzavinos, C. (2016). Hermeneutics. In E. N. Zalta (Ed.), *The Stanford Encyclopedia of Philosophy* (Winter). https://doi.org/10.5860/choice.187763

Mintz, R. L., Loike, J. D., & Fischbach, R. L. (2018). Will CRISPR Germline Engineering Close the Door to an Open Future? *Science and Engineering Ethics*, 1–15. https://doi.org/10.1007/s11948-018-0069-6

National Academies of Sciences Engineering and Medicine (NASEM). (2017). *Human Genome Editing. Science, Ethics and Governance*. Washington, DC: The National Academies Press. https://doi.org/10.17226/24623

Nuffield Council on Bioethics. (2016). *Genome Editing – An Ethical Review*. London: Nuffield Council on Bioethics. Retrieved from http://nuffieldbioethics.org/project/genome-editing/ethical-review-published-september-2016

Nuffield Council on Bioethics. (2018). *Genome editing and human reproduction*. London: Nuffield Council on Bioethics. Retrieved from http://nuffieldbioethics.org/project/genome-editing-human-reproduction

Pridmore, B. (2008). Review of genes in development: Re-reading the molecular paradigm. *Biology and Philosophy*, *23*(4), 579–586. https://doi.org/10.1007/s10539-008-9115-0

Rehmann-Sutter, C. (2002). Genetics, Embodiment and Identity. In A. Grunwald, M. Gutmann, & E. M. Neumann-Held (Eds.), *On Human Nature. Anthropological, Biological, and Philosophical Foundations.* (pp. 23–50). Springer Berlin Heidelberg. https://doi.org/10.1007/978-3-642-50023-7_3

Rehmann-Sutter, C. (2006). Poiesis and Praxis: Two Modes of Understanding Development. In E. M. Neumann-Held & C. Rehmann-Sutter (Eds.), *Genes in Development: Re-reading the Molecular Paradigm* (pp. 313–334). Duke University Press.

Rehmann-Sutter, C. (2008). Genetics, a Practical Anthropology. In M. Düwell, C. Rehmann-Sutter, & D. Mieth (Eds.), *The Contingent Nature of Life* (pp. 37–52). Dordrecht: Springer. https://doi.org/10.1007/978-1-4020-6764-8_4

Rehmann-Sutter, C. (2010). Genes – Cells – Interpretations. What Hermeneutics Can Add to Genetics and to Bioethics. In G. Pfleiderer, G. Brahier, & K. Lindpaintner (Eds.), *GenEthics and Religion* (pp. 12–27). Basel: Karger Publishers.

Rehmann-Sutter, C. (2018). Why Human Germline Editing is More Problematic than Selecting Between Embryos: Ethically Considering Intergenerational Relationships. *New Bioethics*, *24*(1), 9–25. https://doi.org/10.1080/20502877.2018.1441669

Rehmann-Sutter, C., & Mahr, D. (2016). The Lived Genome. In A. Whitehead, A. Woods, S. J. Atkinson,

J. Macnaughton, & J. Richards (Eds.), *The Edinburgh Companion to the Critical Medical Humanities*. Edinburgh: Edinburgh University Press.

Rehmann-Sutter, C., Porz, R., & Scully, J. L. (2012). How to relate the empirical to the normative: Toward a phenomenologically informed hermeneutic approach to bioethics. *Cambridge Quarterly of Healthcare Ethics*, *21*(4), 436–447. https://doi.org/10.1017/S0963180112000217

Sandel, M. J. (2007). *The Case against Perfection: ethics in the age of genetic engineering*. Cambridge, Massachusetts, and London, England: The Belknap Press of Harvard University Press.

Sander-Staudt, M. (n.d.). Care Ethics. In *Internet Encyclopedia of Philosophy*. Retrieved from https://www.iep.utm.edu/care-eth/

Savulescu, J., & Kahane, G. (2009). The moral obligation to create children with the best chance of the best life. *Bioethics*, *23*(5), 274–290. https://doi.org/10.1111/j.1467-8519.2008.00687.x

Schües, C. (2017). The Transhuman Paradigm And The Meaning Of Life. In F. A. Fielding & D. E. Olkowski (Eds.), *Feminist Phenomenology Futures* (pp. 218–241). Bloomington: Indiana University Press.

Schües, C., & Rehmann-Sutter, C. (2013). The Well- and Unwell-Being of a Child. *Topoi*, *32*(2), 197–205. https://doi.org/10.1007/s11245-013-9157-z

Scully, J. L. (2006). Disabled Embodiment and an Ethic of Care. In C. Rehmann-Sutter, M. Düwell, & D. Mieth (Eds.), *Bioethics in Cultural Contexts* (pp. 247–261). Dordrecht: Springer. https://doi.org/10.1007/1-4020-4241-8_17

Van Dijke, I., Bosch, L., Bredenoord, A. L., Cornel, M., Repping, S., & Hendriks, S. (2018, September 1). The ethics of clinical applications of germline genome modification: A systematic review of reasons. *Human Reproduction*. Narnia. https://doi.org/10.1093/humrep/dey257

Voormolen, S. (2019, March 8). Waarom greep niemand in bij de crispr-baby's? *NRC Handelsblad*. Retrieved from https://www.nrc.nl/nieuws/2019/03/08/babies-born-waarom-greep-niemand-in-a3952575

Whitehead, A., Woods, A., Atkinson, S., Macnaughton, J., & Richards, J. (2016). *The Edinburgh Companion to the Critical Medical Humanities*. Edinburgh: Edinburgh University Press.

Glossary

A short glossary of relevant terms from the biomedical field is found below.

Embryo = An organism in the first stages of its development after fertilisation. (NB: A human embryo is referred to as *foetus* in the later stages of prenatal development).

CRISPR-Cas = A biomolecular system that can be manipulated by scientists to make directed and precise changes to the genome of an organism. See *genome editing*.

Gamete = Germ cell (egg or sperm cell) prior to fertilisation.

Germline editing = Short for human germline genome editing; process of making precise and heritable changes to the genetic structure of early human embryos (or human germ cells). As a reproductive technology (still hypothetical) it would likely rely on IVF and PGD. Compare *genome editing*. See also *IVF* and *PGD*.

Germline = Lineage of cells within an individual organism that gives rise to germ cells; or, lineage of germ cells connecting generations of an organism. Compare *somatic cells*.

In vitro = Taking place in a laboratory setting; taking place outside a living organism.

IVF = Short for *in vitro* fertilisation or (in popular terms) test-tube fertilisation; reproductive technology to fertilise an egg outside the human body, before placing back the resulting embryo into the womb.

Life sciences = The scientific study of biological processes in living organisms, often on a molecular level.

PGD = Short for preimplantation genetic diagnosis; reproductive technology which allows to screen and select embryos created through IVF according to their genetic characteristics. See also *IVF*.

Somatic cells = Cells of the adult body that have differentiated to perform a particular function; any cell of the body that is not part of the germline. Compare *germline*.

Zygote = Fertilised egg cell; embryo in the first stages of its development. See *embryo*.

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