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Rules for the digital human park

Two paradigmatic cases of breeding and taming human beings: Human germline editing and persuasive technology

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1 The digital human condition

> For all previous millennia, our technologies have been aimed outward, to control our environment. (…) Now, however, we have started a wholesale process of aiming technologies inward. Now our technologies have started to merge with our minds, our memories, our metabolisms, our personalities, our progeny and perhaps our souls.
>
> Joel Garreau (2004, 6) in *Radical evolution*

1.1 Being intimate with technology

We have become very intimate with technology (Van Est 2014). We welcome technology to nestle itself between us, into us and very close to our bodies. Through these technologies we constantly inform the outside world about our body and behavior. We are monitored from the cradle to the grave: our mobile phones can indicate when the ovulation takes place, we use caloric intake apps, and smart devices are made to count our heartrates, register what we gaze at and check out whether the emotions we show are true or false. Even before birth, still in the test-tube phase, we are able to identify genetic defects or talents in embryos created through IVF. Consequently, our bodies and our behavior have become objects of technological intervention. Recent developments in the field of persuasive technology and human germline editing illustrate this.

This human-machine merger presents a new phase in the information society, which is enabled by the digitization of life. A key characteristic of information technology (IT) is that it blends with all kinds of existing technologies and processes (Castells 1996). We would like to discern four important types of IT convergences (see Table 1). Digitization of production processes is enabled by mechatronics; the mix of mechanical engineering and electronics. Digital communication presents a second form: information and communication technologies combine in 'ICT', enabling for example the mobile internet. Many IT firms and authorities expect that over the next two decades the internet will converge with the physical world. Physical products will be expanded with an internet address, sensors, computational power, and communication facilities. The Internet of Things implies the digitization of the physical world. Finally, IT is blending with biology or living systems, including humans. From a technological perspective this implies that information technology, aided by micro- or nano-sized components, fuses with bio- and cognitive technology. This is often popularly termed NBIC-convergence.

Convergence	Areas converging	Digitization of
Mechatronics (robotics)	Mechanical engineering and electronics	Production processes
ICT (including the internet and mobile telephony)	IT & communication technologies	Information and communication processes
Internet of Things (info and nano *or* bits and atoms)	Internet and physical world	Value chains
NBIC convergence (nano, bio, info, cogno)	IT and biology	Life processes, including human biological, cognitive and social processes

Table 1: Overview of four crucial IT convergences (Source: Van Est & Kool 2015, 47).

In essence, NBIC convergence implies an increased interaction between the life and physical sciences, which constitutes two bio-engineering megatrends: biology becoming technology and vice versa (Van Est & Stemerding 2012). Biology becoming technology points to new engineering tools which allow for more far-reaching interventions in living systems, allowing the human body and brain to be controlled as if they are machines. Human germline editing clearly fits this first trend. The second trend "technology becoming biology" entails the engineering ambition to introduce lifelike features, such as self-repair, cognition and learning, into technology. This is illustrated by persuasive technology, which assumes a human-like style of agency aimed at for example anticipating on or influencing human behavior.

When we look at our own techno-human condition, NBIC enables the digitization of human life, including physiological, cognitive and social processes, and supports three tendencies. First, human beings are more and more seen as machines, which can be maintained, repaired and even upgraded. Next, machines get more and more human-like features. And third, machines penetrate into our privacy and social life and increasingly influence how humans interact. These tendencies all decrease the distance between ourselves and technology. In this digital age, we humans have become techno-humans, mixtures of man and machine, cyborgs. This intimate technology revolution creates a battle for our body and behavior and therefore brings up many political and ethical questions, and one of the most sensitive relates to technologies that aim to alter our germline or behavior.

1.2 Being conscious about breeding and taming

> The domestication of man is the great unthinkable, from which humanism from antiquity to the present has averted its eyes.
>
> Peter Sloterdijk (2009/1999, p. 23) in *Rules for the human zoo*

We seem to have difficulties truly facing the defining impact technology has on our human condition, and taking explicit responsibility for its governance. The German philosopher Peter Sloterdijk (2009/1999) met with a lot of opposition when in 1999 he dared to talk in terms of 'breeding' and 'taming' human beings in his Elmauer lecture *Rules for the human zoo*. According to him, humanism has always been about "the taming of men", by means of the instructive value of books:

"[H]umanism's hidden thesis is: reading the right books calms the inner beast" (Sloterdijk 2009/1999, 15). Sloterdijk claims that besides 'taming' people into being right citizens by means of persuasive texts, we are developing the technical means to genetically engineer our offspring. Instead of ignoring technologies, like prenatal embryo selection and human germline editing, there is a need to debate about how humanity could best use these new breeding technologies.

Strangely enough, Sloterdijk did not problematize the actual taming of people, although there are many technological means to 'tame' people besides books: think for example of electronic lifestyle coaches, which help their users attain personal goals, for example weight loss, financially healthy behaviour or environmental awareness (Kool et al. 2015). Maybe this gap reflects the state of the art of the technology at the end of the 20st century. When Sloterdijk summoned his colleagues to fundamentally reflect on "rules for the maintenance of the human zoo", he was probably aware of the Human Genome project as an early example of the convergence between biology and IT, but not about the fact that a new vision of the future role of computer technology was being concocted: ambient intelligence (cf. Aarts & Marzano 2003). The term 'ambient intelligence' (AmI) refers to invisible 'smart' technology embedded into the everyday human environment, or even the human body itself. Since then the AmI-vision has strongly shaped the European IT research agenda, and now dominates the innovation strategies of most of the global IT companies. The technologies in place to make environments 'smart' and adaptive are sensors, internet, cloud technology, big data, machine learning, et cetera. According to Verbeek (2009, 239), these information technologies challenge us "to tame the taming". So besides a conscious breeding politics, we also need to develop a conscious politics of 'taming' human beings by means of technologies.

1.3 Being domesticated by big data

The digitization of human life (as partly driven by NBIC convergence) is delivering the technologies to domesticate human beings. Digitization is guided by an informational or cybernetic worldview, that is guided by programmability and manipulability (De Mul 1999). Cybernetics assumes that mechanical, organic, cognitive, and social processes can all be described in digital terms, and that by simulating such processes it will be possible to intervene in them. Whereas the raw materials of the industrial revolution were cotton, coal, and iron ore, people form the raw material of the intimate technology revolution (Van Est 2014). We are first being digitally measured, think about digital data on our genetic makeup, thoughts, feelings, preferences, conversations, and whereabouts. These data are not gathered without purpose, but are often used to profile human beings in all kinds of ways with the explicit goal to intervene into human processes. These three steps in the digitization of human life – measuring, profiling and intervening in humans – link directly to the three general processes that

make up the value chain of big data: collection, analysis and application (cf. Roosendaal et al. 2014). The three processes together create a digital or cybernetic feedback loop.

Table 2 illustrates schematically how in the field of breeding and taming, we as human beings use big data to digitally domesticate ourselves. In the domain of breeding, the DNA code plays a central role. Collecting the DNA of human embryos created through IVF and mapping and storing this genetic data in a biobank is a necessary step before analyzing an embryo's genetic profile. Such genetic diagnosis can lead to embryo selection prior to implantation, but is also needed for human germline editing for either somatic or research purposes. A biological sample that can be analyzed for DNA structure and protein levels can also be applied in the domain of taming humans. Personal genetic information can be used to determine the chances of getting ill and provide incentives for preventive lifestyle changes. There are many ways to measure and diagnose the health condition of a person, and increasingly these biomedical technologies are applied outside the medical domain, for example by personal health devices or smart clothes (Van Est et al. 2014). Besides bodily functions, digital technology can quantify various types of behavior, emotions and activities. Based on the analysis of all these data smartphone apps may offer advice about many aspects of our lives, ranging from finances, eating and car driving behavior, relationships and social interactions with others, to lifestyle and energy consumption (Kool et al. 2015).

Elaborating on Sloterdijk's notion of the human zoo or park, it is fair to say that we are living in a techno-human park, and given the increasingly pervasive role played by digitization therein, we might as well say that we are living in a digital human park.

Type of human domestication	**Digitization of human life / Big data value chain**		
	Measuring humans/ Data collection	**Profiling humans / Data analysis**	**Intervening in humans / Application**
	Measuring humans	Profiling humans	Intervening in humans
Breeding human beings	Mapping the human genome through DNA sequencing	Genetic profiling	Human germline editing prior to implantation
	Mapping the human genome	Preimplantation genetic diagnosis (PGD)	Embryo selection prior to implantation
Taming human beings	Genetic testing, e.g. direct-to-consumer	Personal genetic testing report	Lifestyle management (prevention)
	Physiological aspects, e.g. heart rate, blood pressure, glucose rate	Personal health diagnosis	Lifestyle management (prevention)
	Cognitive, social and emotional aspects	Social, emotional and behavioral profiling	E-coaching, neuro-marketing
	Consumer behavior	Consumer profiling	Personalized advertisements

Table 2: Some examples of digital human domestication through big data.

1.4 Two paradigmatic cases

In this paper we examine to what extent the rules of the digital human park are being debated and created on national, regional (in particular European), and global levels. We aim to get to grips with the processes of rule-making for the domestication of human beings. To do that we reflect on two paradigmatic cases of breeding and taming technologies, namely human germline editing and persuasive technology, respectively. We describe the ethical debates evoked by recent developments in those two fields and reflect on those current discussions by means of a longer term perspective. One important historical line, in this respect, is drawn by the human rights perspective. For example, in response to the horrors of the Second World War, the Universal Declaration of Human Rights, was adopted and proclaimed in 1948 by the General Assembly of the United Nations. We will study to what extent the human rights perspective is shaping how society deals with breeding and taming technologies.

Chapter 2 describes the ethical debate evoked by new developments in the field of human germline editing. We study the extent to which the current debate reflects the long-standing debate on 'designer babies' and the use of genetic technologies for doing medical research, and the extent to which new issues are raised. We analyze how earlier technological developments, like recombinant DNA and IVF, triggered ethical and political debates, and to what extent these led to (inter)national regulatory frameworks that anticipated new technological capabilities. Some argue, however, that as long as the anticipated technologies are not yet safely into place, it is relatively easy to ban them. But what will happen when, as in the case of human germline editing, technology catches up? Will it put pressure on or strengthen existing frameworks?

Chapter 3 focuses on persuasive technology. Like many technologies, persuasive technology is enabled by a wide set of other technologies, ranging from sensors to robotics, and artificial intelligence. We will describe how persuasive technology leads to new types of ethical issues, in particular new types of privacy-related issues. In contrast to genetic engineering technologies, which have been debated from an ethical perspective for over four decades, intimate information technologies, like persuasive technologies, have rarely been acknowledged by the political system as needing critical ethical reflection and political debate.

Having considered the two paradigmatic cases, in chapter 4 we draw some conclusions about how humanity, so far, is making the rules for the digital human park.

2 From mapping the human genome to editing the human germline

> It has been only about a decade since we first read the human genome. We should exercise great caution before we begin to rewrite it.
>
> Eric S. Lander (July 2015) in *The New England Journal of Medicine*

Our genetic makeup has become a potential object of technological intervention. Artificial reproductive technologies, in combination with the mapping of the human genome, have created an ever-widening window for diagnosis, screening, selection and modification of our genetic traits. With this development, the long conceived and debated possibility of germline engineering is almost coming within reach. This prospect has again become the subject of vigorous debate as a result of the emergence of CRISPR[1], a technology which enables the 'editing' of the genome in living cells with unprecedented ease, low cost and promised precision. This chapter seeks to understand the debate that has been stirred by the new prospects for human germline engineering in the context of an already long-standing bioethical debate; a debate which not only has been responding to, but also has been anticipating the increasing possibilities for engineering human biology and the human genome. We discuss how current regimes of regulation are informed by the human rights perspective and ask ourselves how to deal with the new prospects for human germline editing in the light of these established regimes?

2.1 Redesigning the human genome

Although genome sequencing and genome-wide association studies have over the years provided more and more information on the human genome, until very recently it was difficult to act upon that information by intervening in a genome (Baltimore et al. 2015). The revolutionary promise of CRISPR is that it provides us with the tools to specifically and efficiently adapt the genomes of bacteria, plants and animals. When applied to humans, this may involve both somatic and germline applications. One example of a somatic application would be the modification of stem cells designed to replace white blood cells that heighten resistance to HIV. CRISPR may also be used to modify human embryonic DNA in order to adjust specific mutations associated with genetic disease. In 2015, Chinese scientists reportedly tried to genetically edit a human embryo (Liang et al. 2015). Such changes to the human germline would have implications not only for the individual that would emerge from the embryo, but also for its genetic heirs. Consequently, the discovery of CRISPR seems to give Sloterdijk's (2009/1999) appeal at the end of the 20th century to constitute rules for 'breeding' human beings new relevance.

[1] CRISPR-Cas9 in full. See Liang 2015. Later in 2015 an alternative to the Cas9 enzym – Cfp1 – was described as even more promising. See Zhang 2015.

Interestingly, when Sloterdijk made his plea, human breeding rules that anticipated the possibilities of human germline engineering already had been or were being established. In particular, these rules were developed within the context of human rights frameworks. For example, the UNESCO Universal Declaration on the Human Genome and Human Rights (1997) states that the human genome should be seen as "part of the common heritage of humanity". And according to Article 13 of the Oviedo Convention drafted by the Council of Europe in 1997, an intervention seeking to modify the human genome may only be undertaken for preventive, diagnostic or therapeutic purposes and only if its aim is "not to introduce any modification in the genome of any descendants". Moreover, within the European Union, we can find a shared rejection of eugenic practices and cloning of human beings, both deemed to be in violation of human dignity, according to Art. 3(2) of the Charter of Fundamental Rights (2000).

Let us return for a moment to the CRISPR technology. In March 2015, rumors first appeared that a group of Chinese scientists had endeavored germline modification of human embryos. In anticipation of this feat, two papers by prominent scientists were published in *Nature* and *Science* respectively, which both emphasized the need for a cautious approach and argued that clinical applications are currently not justifiable, neither ethically nor scientifically (Lanphier & Urnov 2015; Baltimore et al. 2015). This was soon followed by the publication of a paper by Liang et al. in April 2015, describing the use of CRISPR in a largely unsuccessful attempt to genetically edit a human embryo, from which the researchers concluded that the technique is still "too immature" and to which scientists, ethicists and policymakers were quick to respond (Liang et al. 2015; Cyranoski and Reardon 2015).

Why, if the experiment was basically a failure and the possibility of human germline engineering has long been foreseen, and rules have been set up in anticipation of this potential, did the Liang paper stir such commotion? One reason is no doubt that the actual occurrence of genome editing in human embryos drives home with force the realisation that this is a real potential: we really do have the technological capability to change the genetic makeup of humans. Indeed, the new and emerging gene editing technologies are pushing the agenda towards the possibilities and dangers of human germline engineering, thus challenging the rules that have been established about the human genome from a human rights perspective.

2.2 Safety and desirability

The unprecedented possibilities of CRISPR create opportunities for scientists in any part of the world to do all kinds of experiments, raising and amplifying the fundamental question of what types of human genome editing should be allowed. After the publication of the aforementioned paper by Liang et al. (2015) scientists, policy makers and ethicists were quick to take on this question emphasizing

the need for reflection on the possible implications (Cyranosky & Reardon 2015). In this section we discuss the legal and ethical perspectives on human germline editing put forth in response to this paper.

Calling for caution

As mentioned earlier, in anticipation of the research by Liang et al. (2015) two papers were published advocating a cautious approach to germline editing and arguing that clinical applications are currently neither ethically nor scientifically justifiable. The paper by Lanphier et al. (2015) was unambiguously titled "Don't edit the human germline" and called for a moratorium on both research and clinical applications, arguing that human germline editing may lead us down a slippery slope:

> Many oppose germline modification on the grounds that permitting even unambiguously therapeutic interventions could start us down a path towards non-therapeutic genetic enhancement. We share these concerns.

Lanphier et al. (2015) are themselves involved in somatic applications of CRISPR, and fear that germline applications of CRISPR will induce anxieties among the general public, possibly resulting in a ban on both somatic and germline applications.

The second paper by Baltimore et al. (2015) also discouraged genome modification for clinical application in humans. However, the authors recommend that it is important to

> encourage and support transparent research to evaluate the efficacy and specificity of CRISPR-Cas9 genome engineering technology in human and nonhuman model systems relevant to its potential applications for germline gene therapy. Such research is essential to inform deliberations about what clinical applications, if any, might in the future be deemed permissible. (Baltimore et al. 2015)

These scientists thus argue that given the potential for important health care services, the door on further research should not be entirely shut.

Two conflicting views

These two positions roughly represent two conflicting perspectives dominating the debate on CRISPR and human germline editing. On the one side, there are those who applaud the ambition of germline editing, but counsel caution because of safety issues. This position seems to be the dominant point of view. Other commentators, however, are very sceptical of the entire enterprise and reject human germline editing as a legitimate goal. Thus, Francis Collins – director of the US National Institutes of Health and genomics pioneer – argues that human germline editing constitutes a line that should not be crossed. In his view,

> advances in technology have given us an elegant new way of carrying out genome editing, but the

> strong arguments against engaging in this activity remain. These include the serious and unquantifiable safety issues, ethical issues presented by altering the germline in a way that affects the next generation without their consent, and a current lack of compelling medical applications justifying the use of CRISPR-Cas9 in embryos. (Collins 2015)

This quote captures in a nutshell most of the worries expressed in the debate on human germline editing. Other pleas for caution appeal to the same recurring themes: safety, current lack of convincing applications, respect for human dignity including the fundamental rights and freedoms of future generations, and slippery slope arguments. However, the different arguments latch on to different issues: those that refer to the present safety risks of CRISPR technology, and those which question the desirability of any human germline editing. As we will see, the relative weight of these arguments varies according to whether we have clinical applications or research in mind.

Clinical application

Concerning the possibility of a clinical application for human germline editing there is perhaps universal agreement: at this time no expert suggests that clinical application should currently be pursued. The technology is nowhere near safe enough to confidently apply it to actual, living human beings. Of course, as the technology progresses, we may reach a point where it is possible to edit the genome without also causing a number of unintended mutations, although it is not certain whether the technology would ever be entirely safe. And even if the technology is perfected, its applications will likely be limited to those instances where we can predict the outcome with relative certitude. Monogenic diseases, such as cystic fibrosis, beta-thalassemia or Huntington's Disease might conceivably be prevented by means of germline modifications. However, for the vast majority of cases where this might be an option, there are already safe alternatives available, notably preimplantation genetic diagnosis, enabling the screening and selection of IVF embryos for genetic disease (Lander 2015). Applying CRISPR to correct multifactorial susceptibilities for disease, or perform enhancements, seems unlikely in the near future. In particular, the prevention of Alzheimer's, cancer or schizophrenia would require much more knowledge of how multifactorial diseases are caused and what processes underlie the mechanisms leading to illness (Khoury 2013). The expectations, however, vary widely with regard to the question whether multifactorial diseases will soon – or ever – be a feasible target of human germline engineering (Berry 2015; Bosley et al. 2015; Savulescu 2015).

Research on human embryos

Notwithstanding the unanimous rejection of clinical applications of human germline editing at present, there is far less consensus on whether genome editing research on human embryos should be

pursued. On the one hand, it is claimed that research on embryo genome editing may have "tremendous value" in fundamental biological research (Hinxton group 2015). Accordingly, scientists Eric Lander and George Church claim that given the potential benefits, research could and should not be stopped: "today's debate concerns not research (which should proceed) but clinical applications to human beings" (Lander 2015). On the other hand, colleagues like Lanphier et al. (2015) and Collins (2015) have argued that there is a line that should not be crossed. Arguments against human germline editing research sometimes refer to the genome being 'sacrosanct' (Cyranoski & Reardon 2015) or to dangers of the technology that are insufficiently clear. Lanphier et al. (2015) also argue that there are symbolic reasons not to pursue this type of research: such a course may send a clear message that germline engineering is considered morally inappropriate and raise public awareness of the fundamental difference between somatic and germline applications.

The reasons that are brought forward against human germline editing research tend to relate to the nature and future of human 'existence'. For example, Pollack (2015) argues:

> This opening to germline modification is, simply put, the opening of a return to the agenda of eugenics: the positive selection of 'good' versions of the human genome and the weeding out of 'bad' versions, not just for the health of an individual, but for the future of the species.

To a proponent of human germline editing research this indirect charge of eugenics may seem a stretch, or even an insult. It is not likely that a scientist who subscribes to human rights and accepts the principle of free choice and self-determination will identify with the "agenda of eugenics". And indeed many of the reactions to fundamental objections of this kind have been decidedly dismissive. For example, to the previously mentioned slippery slope argument, Savulescu et al. (2015) respond: "nearly all new technologies have unpredictable effects on future generations". To the argument that future generations are unable to consent, Harris (2015) replies that this is also true of any other decision with respect to procreation. In short, the proponents of human germline editing research seem not to be impressed by these more fundamental objections. Maybe this is because the current debate in many respects resembles the long-standing debate on human genetics. In the next section, we will therefore dig somewhat deeper into that historical context in order to better understand the current discussion on human germline editing.

2.3 Two conflicting ethics

For decades ethicists – and other experts – have anticipated the possibility of human genetic modification (Bonnicksen 1994; Carter 2002). In the 1970s, for example, the emergence of in-vitro fertilization (IVF) technology prompted discussion on the ethics of engineering the human genome (Kirby 1984). When during the 1980s preimplantation genetic diagnostics (PGD) became a serious option, concerns about the possibility to select specific traits were pitted against arguments on the

benefits of this technology in combating serious diseases (IBC 2003; President's Council 2004). The notion of the 'designer baby', which emerged in the late 1990s, has served as a powerful image in public discussions about the challenges of reproductive genetics.

Two ethical perspectives

The history of this debate shows an ongoing tension between two different positions each of which are deeply entrenched in distinct foundational and value-laden beliefs. Some applaud the prospect of reproductive genetic engineering, only counselling (pre)caution because of safety issues, while others are much more sceptical and reject the whole idea as a legitimate goal. Now, in 2015, the discovery of CRISPR has once more rekindled this debate. Berry (2007) suggests that discussions about human genetic engineering have historically been framed by a so-called 'reductionist pluralist' perspective versus a 'holist communitarian' one. From a reductionist pluralist standpoint value choices should be made by the exercise of free choice and associated ethical and policy problems can be reduced by achieving a balance of benefit over risks. This view holds that "the issues posed for procreation and parenting by this novel technology (of germline engineering) are the same as for any other bio-medical technology"(Berry 2007, 26). For the holist communitarians, however, this utilitarian risk-benefit approach is inadequate because it does not take into account what is at stake for humanity and society as a whole. They therefore want to engage in a debate about what "the community will abide when it comes to revising the genomes of its future members" (Berry 2014, 27). What divides these perspectives is not, in Berry's view, the usual distinction between utilitarian and deontological thinking, but a tension between an individually and a collectively oriented morality. Whereas an individually oriented morality honours free choice, emphasizing parental autonomy in reproductive decision-making, a collectively oriented morality emphasizes the need for public deliberation and for an anticipatory ethics that is answerable to community norms (see also Bonnicksen 1994).

Medical ethics versus human rights regime

These two perspectives can also be recognized in the two different regimes of biomedical rule-making firmly institutionalized in the 1980s and 1990s on the national and international level: the medical ethics regime versus the human rights regime. The reductionist pluralist view has predominantly taken shape in a *medical ethics* regime of regulation founded on procedures of institutional review and the principle of individual consent. The basic question in this regime is whether a particular intervention in the human body satisfies criteria of safety, informed consent, and, in the context of reproductive medicine, also parental rights and reproductive freedom. In these terms, human germline engineering may be deemed ethically acceptable, especially when a particular intervention may alleviate potential suffering of a (future) human individual (Carter 2002, Hinxton group 2015).

The holist communitarian perspective is clearly expressed in universal and constitution-like *human rights principles*, enshrined in a number of international declarations and conventions on bioethics, human rights and the human genome (UNESCO 1997, 2003 & 2005; Council of Europe 1997). These declarations and conventions represent, as Bonnicksen (1994) has pointed out, the search for a transnational ethics based on the assumption that genes are public resources that constitute a collective genetic 'heritage' or 'patrimony' involving the unity and dignity of all human beings. The implications of human germline engineering are thus societal rather than individual, warranting extra caution and needing collective and anticipatory oversight. In response to the current debate, the UNESCO International Bioethics Committee called for a temporary ban on genetic editing of the human germline, in order to first "consider all the possible consequences on human rights and fundamental freedoms as well as the future of humanity itself" (IBC 2015, p. 12). A more prohibiting position can be found in the legally binding European Oviedo Convention which only allows preventive, diagnostic or therapeutic interventions in the human genome if its aim is "not to introduce any modification in the genome of any descendants" (DH-BIO 2015).

Besides the ideological tension between the two regulatory regimes identified above, these regimes also differ in terms of impact. The medical ethics regime has been strongly institutionalized in medical ethics commissions both on the international and national level. In contrast, there is no such unequivocal impact of the human rights principles enshrined in the international human genome declarations and conventions. A recent survey of relevant legislation and guidelines in 39 countries showed a strong diversity in policies with regard to human genome editing (Ledford 2015). Although many countries have rules that ban germline editing for clinical use, such restrictions are not always legally binding. In other countries rules are more ambiguous and in the countries where clinical use is banned, research is usually allowed. Thus it remains to be seen how current restrictions and guidelines will be affected by new achievements in the field of gene editing. As the Stanford lawyer and ethicist Hank Greely dryly remarked in a comment on official statements that forbid changing the genome "it wasn't hard to renounce something that you couldn't do" (Regalado 2015).

2.4 Rule-making on breeding

In this section we reflect on human germline editing as a paradigmatic case of breeding technologies. Human germline editing is a genetic engineering technology which relies on the power of computer technologies. Its development is guided by an informational world view, and the current situation can be characterized by means of the value chain of big data. The grand scale project to digitize the human genome started in 1990. This is the first step in the digital or cybernetic feedback loop which consists of big data collection, analysis and application. In 2001, ninety percent of the complete sequence of one human genome was known. Only fourteen years later, genome editing in human embryos – the

third step in the cybernetic feedback loop – has actually occurred. Safety concerns are paramount in the current debate about human germline engineering and in this respect there may still be a long way to go before clinical applications become a real possibility. However, some scientists strongly believe that the technical barriers concerning the safety and efficacy of the new CRISPR technology will be solved in the near future (Bosley et al. 2015; Regalado 2015; Buxton 2016). How should we deal with the new prospects for germline engineering? What rules do we need to tame the breeding of human beings?

Our analysis shows that in considering this question society does not have to start from scratch. Ethics is often said to lag behind technological developments, but in the case of human germline engineering it is the other way around. This is largely because the interventionist view that our genetic techniques and data could one day be used to design human babies has historically played a key role both in the public imagination and in ethical debates on biotechnology. Instead of a lack of rules, we have found two important, and significantly different, ethical perspectives and regimes that suggest guidelines for using human germline editing: the medical ethics regime and the human rights regime. So in the event that this technology can be made acceptably safe and effective, we can expect an increasing tension between these two different regulatory values and regimes.

The medical ethics regime – with its emphasis on individual consent and parental reproductive choice – will pave the way for clinical applications of human germline editing. For example, Carter (2002) argues if and when human germline editing can be applied safely and effectively, it will be ethically acceptable and morally desirable. Since germline editing aims to alleviate suffering it satisfies the principle of beneficence and will bestow "a great deal of responsibility on the parents of the embryo in deciding whether germline manipulation would provide the best possible treatment for a genetic predisposition" (Carter 2002, p. 77). Indeed, assuming that the science will continue to progress rapidly, the international Hinxton group expects there will also be "pressure from individuals wishing to use the technology for their own medical, reproductive and other needs" (Hinxton group 2015).

Consequently, the new prospects for germline engineering will increasingly challenge the internationally established human rights and human genome framework, which articulates that no-one can claim ownership of the human genome as an individual (EGE 2016). The aims of germline editing do not only concern the rights and interests of individuals from current generations, but also individuals from future generations. In other words, human genome editing raises questions that cannot be dealt with only in terms of medical ethics principles relating to safety, informed consent and individual reproductive rights. In terms of the international human rights and genome framework, discussions about germline editing also need to take into account the human genome as a common

heritage. Indeed, as expressed in the concluding statement of the recent ICB report on the human genome and human rights, this implies a collective responsibility: "what is heritage of humanity entails sharing both responsibilities and benefits" (IBC 2015, p.29). This position does not exclude the possibility of germline engineering, but emphasizes the need for proper public and political reflection and engagement (see also Jasanoff et al. 2015).

Thus, in facing the prospect of human germline engineering, the main ethics governance challenge is how to move beyond a rising and antagonistic debate between proponents of individual freedom and choice and communitarian modes of thought. As Berry points out, debate across incommensurable systems need not be endlessly fruitless: tension between opposed systems can yield productive change (Berry 2007). In other words, in decisions about how far we should go in tinkering with the human genome there is a need to strike a balance between the values institutionalized in medical ethics and the international human rights and human genome framework.

3 From big data collection to profiling and persuasive environments

> Data protection authorities have a crucial role in preventing a future where individuals are determined by algorithms and their continuous variations.
>
> European Data Protection Supervisor (EDPS 2015, 13).

While genetic profiling, genome editing and germline interventions work towards altering our biological make-up as breeding technologies, digitization is also powering taming technologies aimed at altering our behavior.

In the era of big data the individual is becoming increasingly transparent as a result of the boundless amounts of personal data that are being collected and processed. Online tracking technologies collect detailed profiles of internet users and through social media websites users add even more personal information. And in the physical world numerous smart devices – ranging from smart phones and fitness trackers to smart thermostats, cars and smart public transport cards – are designed to record data on virtually every aspect of our behavior. All these data points can be employed by businesses and governments to infer preferences, anticipate behavior, and personalize environments and information streams. The ever-expanding universe of big data thus powers invisible decisions about the ads and news feeds we see on our screens, how our smart environments interact with us, whether we are suitable for a loan, or whether we might have criminal intents (McKinsey 2011; IBM 2012; OECD 2013).

As such a process of (1) big data collection, (2) analysis, and (3) application emerges, and thus a digital or cybernetic feedback loop is created. In other words, human behavior is (1) read through sensors and tracking technologies, (2) which is subsequently used as the input for data analysis and profiling technologies, and (3) then affects the individual through automated algorithmic decisions, interventions or feedback mechanisms. Central to this process are the profiles that are distilled from big data. Data is abstracted from individuals, matched and mixed with data from other sources and other individuals, and recombined into personal profiles that are used to infer our needs and possible intents. This process of analysis and profiling is not at all transparent and is therefore hard to scrutinize, making it difficult for the individuals to grasp or correct the manner in which they are acted upon by a technological environment. This inscrutability is further exacerbated when the decisions made based upon these profiles are automated through algorithms (cf. Pasquale 2015, Hildebrandt 2012, Kool et al. 2015). So while individuals are becoming increasingly transparent, our technological environment is becoming ever more opaque.

This raises questions as to the extent people are ‘truly’ able to make autonomous decisions in so-called smart environments, whether the reasoning of smart systems can be evaluated, scrutinized

and corrected, and to whether it is still possible to act without being subject to, and influenced by, profiling. These questions are part of a longstanding and ongoing debate about the societal impacts of information technologies. Historically this debate has a strong focus on privacy, and also relates to individual autonomy. To understand the issues and ethical questions currently raised by big data, profiling and pervasive smart technologies, we first need to understand the history of this debate. From there we discuss how developments in big data and profiling challenge our present ethical and regulatory frameworks. Finally we reflect and briefly look forward on what is needed to address these issues.

3.1 Return of the ethical perspective in the privacy debate

The exponential growth of the data universe has led to vigorous debates about how this data should be dealt with. The lengthy discussions surrounding the proposed European General Data Protection Regulation set to replace the Data Protection Directive (95/46/EC) provide a clear example. The current debate centers on privacy and data protection as control over personal information and is strongly motivated by economic considerations. Initially however the debate about data was fueled by broader notions of privacy and the idea of privacy as a human right. We will argue that the return of such an ethical perspective within the debate on the societal impact of IT is urgently needed to safeguard human rights and dignity as we move into a hyper-connected digital age.

The Western debate about privacy is often traced back to the seminal article by Warren & Brandeis (1890) entitled *The right to privacy*[2], in which they argued – facing the advent of the 'mobile' camera – it was time to secure to individuals the right 'to be let alone'. Since then, many interpretations and conceptions of privacy have been formulated. No agreed upon definition exists (Solove 2006). Some conceptions emphasize control over the sharing of personal information (cf. Westin 1967), others emphasize the ability to limit access to the self (from others, such as the state), or stress the importance of privacy as a necessary precondition for personhood, autonomy, intimacy and human dignity (DeCew 2015, Solove 2006).

In addition to its value for individuals, scholars have pointed out that privacy is also a public and social value. Gutwirth (1998) points to the relationship between privacy and other fundamental values in Western democracies, such as freedom of speech, freedom of association, and the balance of powers (state versus citizens). Privacy is as such a cornerstone of western society, affecting individuals' self-determination, autonomy of relationships, behavioral independence, existential

[2] Solove (2006) explains: The 'right to privacy' was first articulated in response to information technology developments (photography and sensationalist 'yellow journalism' by US Supreme Court justice Louis Brandeis and Samuel Warren in Warren and Brandeis (1890).

choices and self-development and the ability to resist power and behavioral manipulation (Gutwirth 1998).

While avoiding a fixed definition, the protection of privacy is part of many conventions, treaties, laws and regulations. In the governance of privacy, the Council of Europe played a defining role, being one of the first institutions to put the protection of privacy on the international policy agenda. The Council of Europe was established in 1949 with the goal of strengthening democracy, human rights and the rule of law throughout its Member States. Inspired by the Universal Declaration of Human Rights (1948), it drafted in the 1950s the European Convention on Human Rights in which article 8 provides a right to respect for one's private and family life, home and correspondence. In the late 1960s the Council established a Community of Experts to advise on the protection of privacy with regards to modern computing advances. Following these efforts the *Convention for the Protection of Individuals with Regards to the Automated Processing of Personal Data (Treaty 108)* was adopted in 1980. For the first time this provided an international legal text which outlined the basic information privacy principles (Bennet & Raab 2006).

Over the years, data protection moved from the context of human rights, to being intrinsically linked to the promotion of economic activity and the operation of international trade. Digital data started to become more important to business operations because of the rise of the computer. As a result, economics started to drive the privacy and data protection debates and ensuing regulatory frameworks. In the late 1970s a transatlantic conflict on privacy protection and international trade emerged within the OECD. Negotiations led to the OECD *Guidelines on the Protection of Privacy and Transborder Flows of Personal Data* (1981). These guidelines represented an important consensus on basic so-called *fair information principles*, like collection limitation, data quality, purpose specification, use limitation, security safeguards, openness, individual participation and accountability. Adequate data protection was seen as a way to enable the free flow of information. The same type of considerations shaped the European Data Protection Directive (95/46/EC) in the mid-1990s. At the time, it was feared that differences in data protection regulation would impede the free flow of information and as such obstruct the EU's internal market (Bennet & Raab 2006).

The Charter of Fundamental Rights of the European Union (REF) - building on the European Convention on Human Rights (1950) formulates a right to privacy (Art. 7) next to a separate right to data protection (Art. 8). The right to privacy put forward in the Charter is more substantive in nature than the right to data protection and offers protection against excessive interference in people's private lives and against restrictions on the freedom and autonomy of individuals (Gutwirth & Gellert 2011). This becomes clear from the approach of the Court of Justice of the European Union (cf. Gutwirth & Gellert 2011). Data protection regulations mainly offer procedural safeguards, by

defining the rules governing the use of personal data (i.e. fair information principles), but offer no substantial safeguards. For example, a defined purpose for data collection could be so broadly formulated that it can be considered privacy invasive (van Lieshout et al. 2012).

Within the regulatory frameworks of the Council of Europe, the OECD and the EU the dimension of control over personal data, or *informational privacy*, has become increasingly important. The informational privacy perspective offers protection to the individual. Behavioral profiling, however, uses data from individuals to create profiles on a group level. Group profiling largely escapes the scope of data protection regulation because the profiles contain aggregate data that are not related to a specific individual. Such profiling can however have far-reaching effects on individual privacy when the individual is matched to a specific profile (cf. Citron & Pasquale 2014; Zarsky 2013). For instance when an individual matches the group profile of a criminal or a potential deviant, this will evidently affect how she will be treated. Big data, profiling and the emerging 'Internet of Things' urgently show that the debate about privacy and how to protect it, should again be informed by a wider perspective that accounts for broader notions of privacy as well as values such as autonomy. In a recent opinion the European Data Protection Supervisor stressed the importance of privacy for the protection of human dignity and stated that: "in today's digital environment, adherence to the [data protection, ed] law is not enough; we have to consider the ethical dimensions of data processing" (EDPS 2015, 4).

In the next section we describe how advances in big data, profiling and the Internet of Things challenge our current conceptions of privacy and autonomy, and urge us to rethink how these values are to be protected in a digital age. The two trends outlined above – individuals becoming ever more transparent, while our digital smart environment is becoming ever more opaque – structure our discussion.

3.2 The transparent individual

The increasing transparency of the individual results from two developments: 1) the pervasive application of sensor technologies throughout our everyday environments; and 2) the fact that all the data collected can be analyzed by increasingly sophisticated technologies, capable of revealing patterns and predicting attitudes, emotions or behavior.

In the past two decades numerous surveillance technologies have penetrated our life-world (Strand & Kaiser 2015). First of all, legitimated by fear of terrorism, the reach of the surveillance state has expanded enormously. At the same time, a big-data business culture has developed in which industry seems to take for granted, in the name of efficiency and customer convenience, that people can be treated as data resources. This commercial surveillance culture has come to flourish in the

virtual world, where businesses have grown accustomed to follow every user's real time Web behavior. With the advent of the Internet of Things this culture of surveillance may well penetrate the physical world. The pervasive use of sensor-equipped technologies is already colonizing personal space to an unprecedented degree. Think of wearable fitness armbands that people use to keep track of activity patterns, heart rate, and stress, e-readers that track peoples reading speeds and habits, or smart home devices that can track TV viewing habits, energy expenditure patterns, food consumption patterns, and even assess moods[3]. As a result more and more actions in the physical world are becoming digitized and therefore traceable and trackable, thus creating the possibility of an environment in which no action goes unmonitored.[4] Big data analysis may make the individual transparent, since even mundane data points can reveal interesting facts about a person. A person's gait, for example, can be analyzed to uniquely identify him or her, or to predict the future risk of cognitive decline and dementia in older adults (Verghese et al 2007). The behavioral data gathered through smart devices can reveal far more than just our daily patterns and activities. Predictions can potentially be made about mental illnesses, health, or even if partners might get a divorce (Mayer Schonberger & Cukier 2013; Matheson 2014; Ciarelli 2010).

To grasp the effect of such an panoptic environment we need to look beyond the narrow concept of informational privacy. Much has been written about continuous monitoring and the effects of surveillance (cf. Lyon 1994). Several authors have suggested that continuous monitoring can have deteriorating effects on the development of identity, individual self-determination, and agonistic opinions fundamental to the functioning of democracy (Schwartz 1999). Westin (1967) states that when individuals know their actions are constantly being monitored, they find it much harder to do anything that deviates from accepted social behavior. This is also knows as the 'chilling effect' of surveillance. Rule et al. (1980) explain that informational privacy and data protection do not provide an adequate framework to deal with these types of questions since they only produce fairer and more efficient use and management of personal data, but cannot contain the ever widening collection of data on individuals. This raises questions about the continuous monitoring that smart environments may introduce, and how to deal with their possible detrimental effects.

Face and emotion recognition technologies provide an interesting example. They extend the abilities of technical systems to analyze people and better adapt their actions to our states. But they might also erode a person's ability to keep her thoughts and feelings private. Through analysis of facial expressions and nonverbal communications accurate predictions can be made about a person's

[3] See EmoSparks AI Home Console http://emospark.com/

[4] It is important to note that there are discrepancies between different parts of the world. In the western world, the opening up of the self is to some extent voluntarily. State initiated projects in for example China and India raise different surveillance issues.

emotional state, such as whether someone is nervous, happy, or telling a lie. Current face reading technology can already distinguish authentic from false expressions with an accuracy of 85 percent, while humans average 55 percent (Andrade 2014). According to Andrade the freedom to not tell the truth 'is an essential prerogative of our autonomy as human beings'. He argues that technology undercuts our autonomy when it takes away the choice to tell the truth or to refrain from showing our true emotions. In this case, developers and customers assume that there is a 'truth' that can be measured and analyzed through technology, while 'truth' is a concept that is often subject to multiple interpretations. If such an assumption becomes widely shared, it would according to Andrade, undermine the ability of people to refrain from telling the 'truth', which is considered a vital part of our social interactions, like when people tell a white lie just to be nice to others.

Technology can thus reveal things that we don't want to reveal ourselves. More than infringing on our personal space, technologies that analyze our social and emotional behavior can be argued to infringe on our mental and psychological space. The Center for Cognitive Liberty and Ethics (CCLE) therefore calls for cognitive liberty: "Cognitive liberty is civil rights for the mind, a legal protection for what and how you think, whether you express your thoughts or not. In many ways, this aspect of cognitive liberty follows from what Warren and Brandeis articulated over 100 years ago: privacy includes a right to psychological integrity." (Boire 2004). Accordingly, several privacy scholars have argued that our concept of privacy should also include privacy of thoughts and feelings. Finn et al. (2013, 5), for example, would like to see that "People have a right not to share their thoughts or feelings or to have those thoughts or feeling revealed." Although the academic debate on privacy is responding to the new ethical dilemmas that arise because of technologies that increase the possibilities of companies and governments to analyze and infer our thoughts and feelings, the attention for this within the regulatory arena, with its focus on the narrow concept of information privacy, is still rather limited.

3.3 The opaque smart environment

While the individual is rendered increasingly transparent, the ability to understand and scrutinize the calculations and analysis performed in the intelligent technological systems around us becomes increasingly problematic. The digitization of behavior has led to the fact that people are represented by countless digital profiles in the databases of social media sites, search engines, smart devices, governments, data brokers, stores, marketing agencies, et cetera. These digital collections of data points can be endlessly shared, recombined, and analyzed beyond our control. French philosopher Deleuze (1992) describes how in the context of digital technology, we have gone from being individuals – irreducible and indivisible entities – to in*dividuals* that can be digitally divided and subdivided endlessly.

Zarsky (2013) argues that the lack of control and transparency of these processes of analysis and application could pose a serious threat to our autonomy. Because a person is not aware of the profiles that are being applied to him, it is impossible to scrutinize how they shape our lives. This could lead to a so-called 'autonomy trap' where a person is steered by the smart environment to act in ways that he or she wouldn't have chosen otherwise. Hildebrandt (2015) adds that a future smart environment might even detect a latent disposition of which a person is not even aware and adapt the environment accordingly, thereby undercutting her ability for conscious reflection on her behavior. She asserts that although our behavior is largely determined by automated cognitive processes, our ability to call them into conscious reasoning and reflect and review them, is what turns us into autonomous agents who are capable of living by their own law, and who can be held accountable for their actions (Hildebrandt 2012, 43). The fact that the automated algorithmic decisions made by technological systems operate outside of our ability for conscious reflection undermines our ability, to object, reflect or reject those computer decisions, and as such corrodes our autonomy within these smart environments. The Facebook experiment in which the number of positive and negative messages in user's news feeds was manipulated provides an example of how changes in algorithms can influence peoples moods and behavior without their conscious awareness (Kramer et al. 2014).

An example of a current smart environment that aims to steer social behavior is the nightlife street Stratumseind in the Dutch city of Eindhoven (Noort & Kist 2015). As part of the experiment called Stratumseind 2.0, the street has been equipped with a wide range of sensor technologies. Cameras detect deviant behaviors of individuals or groups of people, microphones monitor for spikes in sound that suggest aggression, social media traffic is monitored, and through ambient light feedback the people on the street are nudged to act in accordance with the rules of the nightlife street. While the municipality's intentions are likely honorable, such intricate technological systems that operate and make decisions in the background, are opaque and hard to criticize or object to. For instance when a person is flagged by algorithms for possible deviant behavior, the affected person has little way of knowing why his behavior triggered a certain response.

Citron & Pasquale (2014) use the example of automated credit scoring systems to show how people judged by automated algorithmic systems have very limited possibilities neither to assess whether that judgment was correct nor to object to it. A credit score is based upon data from multiple sources, through an opaque process in which the different inputs are rated to arrive at a single credit score. While an algorithmic system might provide a seemingly objective 'score', prediction or profile, these systems are never neutral and can contain serious biases. A study by Carnegie Mellon University, for example, found that male job seekers were much more likely to be offered Internet ads for high profile executive position than equivalent female job seekers (Datta et al 2015). The

researchers could not determine what caused the discrimination due to the limited visibility of the workings of the ad-ecosystem. Dormehl (2014) cites the example of US-resident John Gass, who had his driver's license revoked by an automated facial recognition system that had wrongly flagged his driver's license as a fake id. The Registry of Motor Vehicles claimed it was the individual's responsibility to clear his name in the event of a mistake and argued that the advantages the system offered in protecting the public, far outweighed the inconvenience to the wrongly targeted few. These two examples highlight the opaqueness, the risks of systemic bias and error, and the disempowered position of the individual in relation to algorithmic systems.

In its study *Big Data* (Podesta et al. 2014) the White House stresses the importance of preserving core values, including privacy, fairness, non-discrimination and self-determination. Citron and Pasquale (2014, 6) state that "If scoring systems are to fulfill engineering goals and retain *human values* of fairness, we need to create backstops for human review". As part of the coming European General Data Protection Regulation, data controllers will be obliged to inform individuals about the existence of profiling and its envisaged consequences, and individuals will have the right not to be subjected to automated decision making in case it has significant effect on their lives (Council of the European Union 2015). This could provide important protection for the individual but will only work when a sociotechnical infrastructure of tools and mechanisms to deliver meaningful transparency is developed. Furthermore, algorithms and profiles are often protected by means of trade secret or intellectual property that might hamper these transparency enhancing rights (Hildebrandt 2012 2015). Hildebrandt (2012) argues transparency enhancing tools (TETs) should be developed to inform people of how they have been profiled by smart systems around them, and what the consequences of this profiling are. For instance, the people subject to automated credit scoring, or automated online talent scouting should be informed of the way different data points of their distributed online identities have resulted in an automated software agent making a certain decision. In his visionary work on computing in the 21st century, Weiser (1991) remarked "The most profound technologies are those that disappear. They weave themselves into the fabric of everyday life until they are indistinguishable from it." As technologies in the age of the Internet of Things move more and more into the background, designing meaningful transparency mechanisms might prove a big challenge. Nevertheless, such transparency mechanisms seem to be essential to protect human autonomy.

3.4 Rule-making on taming

In this section we reflect on rule-making on persuasive technologies as a paradigmatic case of taming technologies. Persuasive technologies are information technologies that aim to influence human behavior. Therefore, we placed the upcoming debate on smart persuasive environments in the tradition of the longstanding discussion on the impact of IT on data protection, privacy and autonomy.

We will use the value chain of big data – the digital or cybernetic feedback loop which consists of big data collection, analysis and application – to get to grips with the current situation.

In a nutshell, we argue that in the 1960s and 1970s, the debate focused on data collection and control over personal data (informational privacy). In the 1980s and 1990s there came more attention for data profiling and privacy concerns (cf. Vedder 1998). Today, however, data profiling and the way it is used to intervene in the lives of people, and applied to steer people's behavior, demands our full attention. This realization that the cybernetic loop has come full circle forces us to acknowledge that, besides control over personal data, people need control over how smart environments shape their behavior.

This chapter described two main trends: individuals are becoming ever more transparent, while at the same time our digital smart environments are becoming ever more opaque. The first trend relates to the process of data collection and makes it harder, or even impossible, for people to control their personal data. The second trend refers to the increasing role played by big data profiling and smart feedback environments, and the fact that their opaqueness hampers people from even seeing how they are being influenced. Both trends lay bare weaknesses of current regulatory frameworks and force us to look for a new balance between economic development on the one side and safeguarding individual human values, like privacy, autonomy and equal treatment, on the other.

Need to control personal data

In the 1960s and 1970s, sensitivity to privacy in Europe and the United States increased among citizens and politicians. The issue at stake was the digital registration of personal data, which was mainly collected by manually filling in forms. As we saw, a call for the protection of privacy caused rules to be debated and created, on national, regional and global levels. On the one hand, the human rights perspective plays an important role in those rule-making processes. In this respect, the Convention for the Protection of Individuals of Personal Data as organized by the Council of Europe in 1980, has historically been quite influential. This convention framed privacy in terms of informational privacy. In order to protect personal data in practice the fair information principles were formulated with regard to the collection and processing of data.

This perspective informed the OECD and EU frameworks, but information privacy was not the only perspective influencing them. Namely, during the 1980s data protection became intrinsically linked to the operation of international trade. Both the OECD and EU frameworks tried to strike a balance between economic values (free flow of information between states in order to optimize international trade conditions) and the human rights perspective on privacy.

As individuals become ever more transparent, the aim of the above regulatory frameworks to control personal data is becoming more and more unreal. A first weakness concerns the limited enforceability of data protection rules in a global political economy. Recent rulings, however, such as the rulings of the European Court of Justice on 'safe harbour' in October 2015, and on the territoriality and applicability of EU rules to a search engine (Google Spain SL, Google Inc. v Agencia Española de Protección de Datos, Mario Costeja González)[5] – show that EU data protection laws can be enforced. Besides, there is the growth of a generic surveillance culture, where not only states employ surveillance technologies on a massive scale, but also firms and citizens. From a technical point of view, we have witnessed an immense growth in the ways people can be monitored: from geolocation to recognizing emotions. These new technologies require us to think about how we can secure and protect privacy of thoughts and feelings, which are essential to be able to autonomously develop our identities and our relationships with the world around us. Finn et al (2013) describe new types of privacy for the information society, such as privacy of personhood, privacy of thoughts and feelings, and privacy of location and space. Securing protection for these 'new' dimensions of privacy presents a big socio-cultural, political and regulatory challenge.

Need to control profiling and smart environments

Profiling and the rise of smart persuasive environments challenges our privacy and autonomy at an even more fundamental level. Namely, current data protection frameworks have focused on data collection and the fair use of data and are led by the fair information principles to safeguard privacy. At the time these principles were articulated the virtual world was seen as a rather inactive add-on to the physical world. Over time these principles have been examined and found to be still valid for a future of new technologies and globalization (Article 29 Working Party and Working Group on policy and justice 2009). Nevertheless, nowadays the offline and online worlds have merged, forming an on*life* world (Floridi 2015); in other words IT has changed from being a tool to becoming a defining characteristic of our lives. Moreover, the IT system has become a cybernetic system, and has assumed a kind of artificial agency. As a result, smart environments powered by big data-driven artificial intelligence, provide many ways of profiling people and subtly steering their behavior. The consequences of this radically new situation for human rights like privacy have not yet been given enough attention in public, political, ethical or human rights debate, let alone been well thought-out.

Profiling forms one challenge, since current regulatory frameworks on data protection are designed to offer protection at the level of the individual, while profiling technologies tend to operate on a group level. An important regulatory challenge, therefore, is how protections can also be

[5] http://curia.europa.eu/jcms/upload/docs/application/pdf/2014-05/cp140070en.pdf

designed on a group level. Secondly, non-transparent smart environments raise fear for the Kafkaesque scenario of a seemingly arbitrary smart environment that interferes with our preferences and anticipates our behavior. Above we have argued that if we are not able to find mechanisms to increase transparency and control over automated profiling and decision making software agents, we might find ourselves in an 'autonomy trap'. Finally, the value of equal treatment may be under threat. Therefore, policy makers need to think about ways to prevent discrimination and exclusion in the on*life* world.

Need to update the ethical debate

Amongst scholars there is discussion whether current regulatory frameworks are able to safeguard our human rights in this digital era. The new European general data protection regulation aims (amongst other things) to strengthen individuals' rights, and strengthen responsibilities and accountability for those that use and apply personal data. The arrival of the on*life* world challenges us to move beyond the current concepts of data protection and informational privacy, to a broader perspective which takes into account values like autonomy, fairness and human dignity. But before regulatory frameworks can be adapted, there first is a need for an ethical debate amongst companies, scientists NGOs, governments and politicians. Just like in the 1970s, the ethical and human rights community should take leadership and start to develop this highly needed broader view on smart environments and privacy informed by fundamental human rights and values.

4 Rule-making for the digital human park

Inspired by Sloterdijk's (2009/1999) wake-up call at the end of the last century, this paper reflects on the "rules for the maintenance of the human zoo". Since digitization (of human life) plays a central role in our society it is fair to say that we live in a *digital* human park. This digitization process is guided by an informational worldview, and constitutes of a myriad of cybernetic feedback loops that consist of measuring, profiling and intervening in humans. NBIC convergence strongly increases the measurability, analyzability and make-ability of human life. Related to this, the collection, analysis and application of big data plays a major role in the way we domesticate ourselves.

The digitization of human life has developed to such an extent, that we are challenged to develop a conscious politics of breeding and taming. To study how man so far has dealt with this challenge, we researched human germline editing and persuasive technology as two paradigmatic cases of breeding and taming technologies, respectively. In this concluding chapter, we first reflect on the two cases and conceptualize rule-making on breeding and taming as an ongoing balancing act between individual and collective values. We also put forward the question of where, in a world in which humans are becoming more and more intimate with machines, the human self is located, and related to this where human rights should be located.

4.1 Global incoherent regulatory patchwork

A first conclusion may be that the role of technology in the breeding and taming of people has neither gone without ethical reflection nor public and political debate. Over the last half a century the debate on designer babies and IT and privacy has been on the public radar almost continuously. New technological breakthroughs in the field of biotechnology (ranging from rDNA, cloning, gene sequencing and synthesizing to CRISPR), and information technology (ranging from data storage, sensors, mobile phones, machine learning and face recognition) over and over light up these debates in the media, as well as among citizen groups, artists, and technical, ethical, legal and policy experts.

Moreover, to a certain extent a conscious breeding and taming politics can be discerned. In other words, rules for the maintenance of the human park are being debated and created, both on the national, regional (e.g. European) and global level. With respect to rule making at least three layers can be distinguished: basic human rights, legal instruments, and social and cultural rules. There is a complex interplay between those levels. For example, in the field of IT and privacy the 1980 Convention for the Protection of Individuals of Personal Data organized by the Council of Europe drafted the fair information principles, which could be used as a kind of moral template by the OECD and the EU to set up more binding regulatory frameworks.

At the beginning of their study on the global governance of privacy, Bennett and Raab (2006) outlined four possible visions of privacy: the surveillance society, an incoherent and fragmented patchwork, a world of privacy haves and have-nots, and a trading-up to global privacy standards. At the end they conclude that the second scenario is the most plausible: "a more chaotic future of periodic and unpredictable victories for the privacy values as the spotlight focuses on a particular practice for a brief period and then moves on" (Bennett & Raab 2006, 295). The same counts for the global governance of human genome editing. Sparked by new developments, like IVF, embryonic stem cells and reproductive cloning, there have been various waves of legislation. This has resulted in the current regulatory mosaic, where in some countries, experimenting with embryos is a criminal offence, whereas in others almost anything is allowed (Ledford 2015). So although a conscious breeding and taming politics can be discerned at the level of nation-states, it so far results in a rather fragmented patchwork of policy instruments and governance structures. As a result, the rules that exist on a national or even regional level only have limited enforceability in a global political economy.

4.2 Rule-making as a balancing act between values

In the debate on human germline editing and persuasive technology a complex set of values plays a role (see Table 3). Rule-making requires thoughtful balancing between these different individual and collective values and the related interests of different actors. If we consider values as drivers of a certain socio-technological development, some values may be denoted as accelerator values that legitimize a certain development, while other values act more as brake values that are used to legitimize slowing down, setting the conditions for or even banning a certain development.

Human germline editing: Unsafety favors the brake values

In the debate on human germline editing, safety plays a central role. There is consensus among scientists that this technology is not yet safe enough. Preventing harm is an important value and the current risks involved clearly hamper the application of human germline editing, but also favors other brake values in the current debate. One influential view – see for example UNESCO Universal Declaration on the Human Genome and Human Rights (1997) – claims that the human genome should be seen as part of the common heritage of mankind and should not be commercialized. The child's right to self-determination or an open future is another, both individualistic and collective, value that is often used to oppose human reproductive cloning and human germline editing. These values conflict with the individual right to procreate and the parent's right to reproductive freedom.

So far, the notion of the human genome as a common heritage of humanity dominates the human rights perspective on designer babies. New technological breakthroughs like gene editing are used as windows of opportunity to reinforce the importance of that collective value. For example, the

UNESCO International Bioethics Committee (IBC 2015) called for a temporary ban on genetic editing of the human germline. Some actors will agree with this view for pragmatic reasons: to avoid that the debate on banning human genome editing might lead to a ban on research. Without such a ban on research, the technologies needed to genetically engineer human embryos will further develop. It is therefore imaginable that once it will be technically possible to safely genetically engineer human embryos. Such a situation will really bring the conflict between the brake and accelerator values, as summed up in Table 3, to a head.

Persuasive technology: The need for striking a new balance

Exactly that has been the case in the field of IT and privacy since the early 1980s. Before that time the human rights perspective on privacy reigned supreme. But afterwards there was a pragmatic need within the OECD and European Union for a balanced consideration of both economic development as a collective value and privacy as both a collective and individual value. The rise of smart persuasive environments asks for a new balance. This requires us to rethink and conceptualize anew what we mean by privacy and how it can be safeguarded. The fair information principles, which stem from a period with manual collection and automatic processing of personal data, are no longer sufficient to deal with the real-time collection of data via sensors and smart environments. The agency and opacity of smart environments force us to move beyond informational privacy, and look for ways to control how these environments not only collect data, but also profile us and steer our behavior.

Type of human domestication	**Individual and collective values as drivers**	
	Accelerator values	***Brake values***
Breeding of humans (human germline editing)	• Safety • Individual right to procreate • Parent's right to reproductive freedom • Economic development • Freedom of inquiry	• Risk • Human genome as common heritage of mankind • Child's right to self-determination or an open future • Avoiding commercialization of human genome
Taming of humans (persuasive technology)	• Economic development • Public security • Convenience • Empowerment	• Informational privacy • Autonomy / self-development / personal freedom • Fairness • Privacy as a collective value

Table 3: Overview of various values that play a role in the debate on human germline editing and persuasive technology as paradigmatic cases of breeding and taming humans.

4.3 Machines in humans, humans in machines

> Rather than opening up practices of the Self, allowing individuals to shape their own lives, Big Data repositories providing reference data (standards for normality) become an electronic panopticon, a molecularised super-ego, the 'voice of conscience' of the terabyte age, the Big (digital) Other.
>
> Hub Zwart (2015)

The case studies showed a marked difference in the way we deal with human germline technology versus persuasive technology. Although the technology to genetically engineer human embryos is far from being mature or safe, the interventionist view – the view that our genetic data could one day be used to design human babies – has for long played a key role in the public imagination and ethical debate on biotechnology. Decoding the human genome – the first step in the cybernetic loop – is directly linked to the possibility of intervening in the human genome. Or as the transhumanist Gregory Stock bluntly argues: "We have spent billions to unravel our biology, not out of idle curiosity, but in the hope of bettering our lives" (quoted in Garreau 2004, 115). In contrast, the focus in the field of IT has historically been on the collection and processing of big data. And only recently is it being realized that the interventionist view – using data profiling to intervene in human behavior – has to be taken very seriously. So what explains this difference between the way we debate and make rules concerning breeding and taming technology?

This relates to two separate ways in which breeding and taming technologies merge with human beings. Breeding technologies, like human germline editing, intervene in the human body. DNA technologies are invasive technologies that work *inside* the body. Here machines and humans merge in a classical way: technology is put into humans. Although in the field of artificial intelligence, human-machine symbiosis has been prophesied since its beginnings (cf. Noble 1997), this phenomenon so far has not played a significant role. Information technologies were seen as mere gadgets that operate as human tools *outside* the body. We seemingly did not realize that by digitizing human life we were putting humans into machines; by filling in databases we constituted "an additional self" (Poster 1990). Gelernter (1993) used the term *mirror world* to describe this process: the collection of digital representations or profiles of our physical body and behavior in the real world that can be found in the virtual world.

These digital mirror copies provide reference data of who we are and what we might become and provide reference data about what is normal or absurd, good or bad, beautiful or ugly, strong or weak genetic make-up. The digitization of human life thus shapes how we see ourselves and others and the way we behave. By putting humans into machines, we have become "subjects of the normalizing gaze of the Superpanopticon" (Poster 1990, 97-98). Since our digital profiles are stored in the databases of governments, medical centers, social media sites, search engines, marketing agencies, data brokers et cetera, we have become potentially more transparent to ourselves and many others. Our additional digital selves do not belong exclusively to us, and are to a large extent beyond our control; they may empower us, but may also work to our detriment.

4.4 Human rights enhancing machines

> Machines are my posse. They are my machines, my body. Machines serving me should be a civil right. Now the machine is serving Google.
>
> Dave Ackley (2015)

We conclude that a conscious human breeding and taming politics indeed is required. To a certain extent such a politics can be discerned, but so far has led to a fragmented patchwork of policy instruments and governance structures. There is a clear need for moral guidelines on the global level that may not be enforceable, but may guide national efforts to steer developments in the field of human germline editing and persuasive technology. We agree with Greely (Regalado 2015), who said that it is not hard to renounce human germline editing when it still unsafe. But when this technology becomes almost a hundred percent safe, the voice of the proponents will become much louder. Smart persuasive environments are already working around us and force us to strike a new balance between economic development and privacy. Whereas human germline editing is an example of putting technology into humans, persuasive technology is an example of putting humans into technology. We need to understand that both types of human-machine interaction are in need of careful ethical guidance. This was taken for granted for biotechnologies (biology becoming technology), but also applies to intimate information technologies (technology becoming biology), especially when they seek to steer our behavior.

Finally, the ongoing merger of human and machine raises the profound question of where the human self is located (cf. Lyon 1994, 18). This question is relevant because by definition human beings hold human rights, and not machines. But as humans and machines grow increasingly intimate, it becomes harder to assess the limits of the human body and of the self. Accordingly, it becomes harder to determine the boundaries of the human subject which holds human rights. If we put technology, such as deep brain stimulation electrodes or DNA, into our body, does it become part of ourselves? And does safeguarding our bodily integrity also apply to those technologies? It is easy to imagine that in the case of deep brain stimulation bodily integrity as a human right belongs to the human being, including the electrode. But what if that electrode is connected to the internet? Or similarly, what if we put more and more intimate digital data of ourselves (body, brain and behavior) into machines?

We should take very seriously the fact that through these processes we are creating additional selves. This raises the question whether these digital selves should be considered part of the human self, and therefore should hold human rights? What does this imply for safeguarding human rights and where should such safeguarding take place? Academics in the privacy field plea for designing privacy into smart systems. Recently, this idea has become a more prominent issue on the agenda of

policy makers. According to Klitou (2014, 263) “The premise behind privacy by design is that it is “likely more effective to enforce laws/rules at the manufacturer/design-level, as opposed to the user-level”. Privacy by design, or privacy enhancing technology, is an example of the broader concept of value sensitive design, which tries to take account of all kinds of relevant human values, including basic human rights, when designing technology. Maybe one day it will be a basic human right to be served by machines that enhance human rights.

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ANNEX 1:

Concept paper for emerging and converging technologies

Emerging and converging technologies in the biomedical field challenge National Ethical Committees (NECs) to anticipate, identify, and find ways of responding to or managing the ethical issues that arise from these complex technological innovations and convergences, many of which have implications for human rights and human dignity.

The Council of Europe's recently published study of the ethical concerns raised by these emerging and converging technologies (Strand R. and Kaiser M. *Report on Ethical Issues Raised by Emerging Sciences and Technologies*, 2015) provides a useful model for reflection and moving forward. The *Report* frames the main issues and ethical concerns and then uses the notion of 'paradigmatic cases' to work through the implications and ethical concerns of specific technologies.

Two broad types of technologies are increasingly identified by NECs as needing attention: Big Data and germline interventions / human genome editing. The Global Summit paper would use these two broad types of technologies as paradigmatic cases of emerging technologies with each discussed in turn against the background of a broad view on emerging ethical challenges through technical innovation.

While the main purpose of this paper is to provide NECs with an up-to-date background of the issues and how they may be approached, a secondary purpose is to move towards recommendations/ points to consider on these two – and perhaps other – technologies. The paper should be only as technical *vis a vis* the specific science of each technology as is necessary in this paper for the Global Summit of National Ethics Committees. The paper should be of interest to NECS from developed, transitional and developing countries.

Some of the specific points that would be useful for NECs and should be incorporated include:

- What are the implications of Big Data for health interventions and delivery? For the relationship between patients and physicians? For society in general?
- What are the implications (current and in the future insofar as we can imagine them) of germline interventions / human genome editing? What are the potential benefits and what are the risks of CRISPR-Cas9 techniques?
- What are the ethical and also legal implications of altering human genomes?
- What ethical guidance and policies/ opinions / laws have been, and which should be developed to foster advantages and avoid disadvantages of emerging technologies?

- Are current consent procedures adequate?
- When is encouraging restraint the desirable ethical approach and when does it overly restrict innovation?
- Which features are necessary to make governance mechanisms sufficient? Are there examples from countries?
- Considering the global dimension of the issue, there is a need for guidelines and regulation on an international level. What aspects should be considered in reaching such an agreement?