Chapter 5
Science and Technology Governance and European Values

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5.1 Introduction

This chapter is in four parts. The first describes the most fundamental European values as recognized by the Charter of Fundamental Rights of the European Union (EU) and the Treaty of Lisbon. One value that will be discussed in addition to those contained in the charter is that of sustainability. While the idea of sustainable development was included in previous European treaties and instruments, it has been given more emphasis in the Treaty of Lisbon through Art. 3(3) (EU 2007):

> The Union … shall work for the *sustainable development* of Europe based on balanced economic growth and price stability, a highly competitive social market economy, aiming at full employment and social progress, and *a high level of protection and improvement of the quality of the environment* (our emphasis).

A brief historical section will explain how many of these fundamental values attained prominence. Explanation of what exactly these values mean forms the main part of the chapter, followed by a case study section on preimplantation diagnostics.

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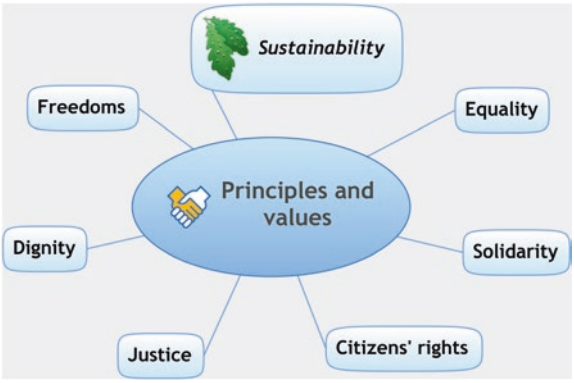


Fig. 5.1 Main principles of the charter of fundamental rights and the treaty on the European Union

5.2 Fundamental European Values

Science and technology policies will succeed best if built on strong ethical foundations. These foundations are being debated worldwide, and the need for effective global governance of science is becoming more and more urgent. Given the democratic backing of the Charter of Fundamental Rights of the European Union and the Treaty of Lisbon (EU 2007), we shall explore fundamental European values and how they relate to science and technology policies (Fig. 5.1).

The EU Charter of Fundamental Rights (EU Charter) was signed on 7 December 2000. Importantly, the charter is legally binding. This was achieved by incorporating a reference to the charter into a binding treaty. Article 6(1) of the Treaty of Lisbon (EU 2007) reads:

> The Union recognises the rights, freedoms and principles set out in the Charter of Fundamental Rights of the European Union of 7 December 2000, as adapted at Strasbourg, on 12 December 2007, which shall have the same legal value as the Treaties.

This reference to 'the same legal value as the Treaties' means that the charter now forms part of the primary law of the EU, and as a result provisions are potentially enforceable through national courts as well as in the European Court of Justice (Barnard 2008). (The scope of the charter is specifically aimed at institutions of the EU and only applies to member states, when implementing EU law.[1])

[1] The field of application is addressed in Art. 51(1) of the charter, which reads: 'The provisions of this Charter are addressed to the institutions, bodies, offices and agencies of the Union with due regard for the principle of subsidiarity and to the Member States only when they are implementing Union law.'

5.3 European Enlightenment

The European Enlightenment was broadly coextensive with the 18th century. The German philosopher Immanuel Kant (1724–1804) described it as a process of moving from superstition, unawareness and blind belief in authorities to progress for humanity through the power of reason (Kant 1990). The term 'Enlightenment' is thus generally used in Europe to describe a process of liberation from traditions, institutions, conventions and norms that could not be rationally justified. Essential ideas associated with this period include the convictions that mastery over nature will lead to the advancement of humanity, that tolerance is a virtue of states needed to maintain public order and that human beings can be perfected through education (Mickel 1986). Amartya Sen summarizes the European Enlightenment as an 'intellectual climate … with [an] interest in reasoned construction of social order' (Sen 2000).

Common to all ideas of the Enlightenment is the core belief that human reason and *not* religious or state authority ought to decide on the norms of ethical, political and social action as well as the differences between truth and error. As a result, some of the values now found in the EU Charter rose to prominence when authoritarian regimes were challenged, especially on questions of freedoms, citizens' rights, solidarity and equality. This was particularly obvious in the French Revolution of 1789, with its rallying cry of 'Liberté, égalité, fraternité' [Liberty, equality, brotherhood].

Immanuel Kant was an exceptionally important figure in the European Enlightenment (Hampson 1982), and he has most often been credited as the father of human rights in their modern sense. In the West, the history of human rights is often told in two different ways. The first takes an inclusive approach, and claims that human rights are based on universal beliefs that can be traced back to most religions (Hampson 1982). For instance, believers in Islam have issued a Universal Declaration of Islamic Human Rights containing 23 rights, including the right to a fair trial, the right to protection against torture and the right to social security (Islamic Council 1981).

On the other hand, 'Islam stresses the submission of the individual to Allah [as] God has rights, people do not…' (Dalacoura 2005). This statement clearly contradicts both the idea of individual human rights and the European Enlightenment belief that one should question religious authorities. Likewise, Buddhism seems incompatible with rights assigned to autonomous individuals, given that it 'denies the very idea of autonomy, continuity and authenticity of the self' (Chan 2005a). Similarly, Confucianism and its focus on virtue (the attainment of *ren* being the most perfect of virtues) links better to ideas of ethics of obligations than to rights; in particular, obligations to respect and care for others (Chan 2005b).

The second approach maintains from the start that the idea of human rights is of Western origin, usually credited to the Enlightenment and specifically to John Locke (1632–1704) and Immanuel Kant (1727–1804).

Analyses of the historical predecessors of the contemporary theory of human rights typically accord a high degree of importance to Locke's contribution.

Certainly, Locke provided the precedent of establishing legitimate political authority upon a rights foundation. This is undeniably an essential component of human rights. However, while the philosophically adequate completion of a theoretical basis of human rights requires an account of moral reasoning that is consistent with the concept of rights, it does not necessarily require an appeal to the authority of some superhuman entity in justifying human beings' claims to certain, fundamental rights. Immanuel Kant provides such an account (Fagan 2005).

How does Kant justify his belief in universal human rights—in other words, in individual rights irrespective of gender, race, ethnicity, sexual orientation etc.? For Kant, human beings have the capacity to act morally: their ability to separate good and bad actions depends on their faculty of reason, and only because they are rational is it possible for them to decide between right and wrong. This human ability to be rational and to make decisions leads to a particular way of looking at the world. As Kant says in a famous passage from the *Metaphysics of Morals* (Kant 1996):

> [B]ut a human being regarded as a person, that is, as the subject of a morally practical reason, is exalted above any price; for as a person… he is not to be valued merely as a means to the ends of others or even to his own ends, but as an end in himself, that is, he possesses a dignity (an absolute inner worth) by which he exacts respect for himself from all other beings in the world.

In justifying human rights through the human ability to reason, Kant also introduces a value which has since become central to European value systems, namely that of dignity. Humans have dignity *and* possess human rights because of their 'rational nature in its capacity to be morally self-legislative' (Wood 1999). Kant therefore based individual, universal human rights on human dignity understood as the ability to be self-legislative. (For a broader view of dignity, see below.) This is why he is often regarded as the Father of Human Rights, which are now also reflected in the EU Charter.

The value of dignity was given added importance through the horrendous acts of Nazi doctors during the Second World War and other harmful, highly exploitative medical experiments. As a result, the 1949 German Constitution now places respect for human dignity ahead of all other values, enshrined in Art. 1(1): 'Human dignity shall be inviolable'.

When European Enlightenment ideas of the questioning of authorities (political and religious), mastery over nature, belief in human progress and individual autonomy are combined, it is clear why the development of science and innovation has accelerated in the West since the 17th century.

For instance, the optimistic notion of *progress* was paramount to the development of modern science. It is often said that Western philosophers still debate Aristotle's *Nichomachean Ethics*, while his scientific assumptions (for instance, that the void around the earth is filled with aether) have long since been discarded.

Only with the wider use of nuclear energy and nuclear deterrence (Lehming 1991) in the 1950s and 1960s, and later with the development of genetically modified organisms, was the belief in social progress through science questioned among broader populations in Europe. The first European Green parties emerged

in the 1970s, and the most powerful—the German Green Party—has been sharing government responsibilities since the 1980s either locally, regionally or nationally, based on opposition to nuclear power and genetic modification. The value of sustainability derives from this movement, which is active throughout Europe.

In addition to the Green movement's subversion of an uncritical belief in science, it is today widely acknowledged that the European Enlightenment, with its emphasis on human progress, human domination over nature and the importance of reason, nourished the European colonial enterprise. Indian scholar Sanjay Seth, who heads the London-based Centre for Postcolonial Studies, writes (Seth 2011):

> Armed with the certainty that it possessed nothing less than universal Reason, Europe could proceed with its colonial conquests, no longer principally in the name of bringing the true word of god to the heathen, but rather in the name of bringing Enlightenment and civilization to the benighted.

While Seth emphasizes that 'neither the modern age nor Europe has had a monopoly on … dogmatism' (Seth 2011), he notes that the belief in tradition-free reason, which does not realize the cultural context of ideals and practices, made colonialism possible.

At the same time, thinkers from different continents continue to stress a key idea from the Enlightenment period, namely humanism: the belief that all individual human beings are important and deserve respect. For instance, according to Nigerian scholar in African Studies M.O. Eze, a 'peculiar form of African humanism' (Eze 2011) can be identified in the philosophy of Ubuntu. 'Ubuntu' is often summed up as meaning 'I am because you are' and the belief system emphasizes 'compassion, generosity, honesty, magnanimity, empathy, understanding, forgiveness, and the ability to share' (Eze 2011). According to this system of thought, human beings flourish best through supportive relationships with others.

The new humanism, according to Mexican professor of political and social philosophy Oliver Kozlarek, is a humanism that does not stop at recognizing cultural differences in postcolonial times, but instead looks for normative perspectives that all humans can agree upon. Importantly, these perspectives need to filter down into everyday life and practice (Kozlarek 2011). Once this is achieved, humanism will have succeeded in ensuring that human beings flourish in a culturally diverse world.

5.4 European Fundamental Values

5.4.1 Justice

The unjust ignore justified rules, exploit others and are enemies to equality, according to Aristotle (1985). An earthquake or a hurricane cannot be just or unjust, nor can a lion or a monkey. Even a human being, if entirely alone on a desert island, cannot be just or unjust. Justice is a principle that requires human

interaction. It can characterize agents and their actions, social rules or states of affairs (Pogge 2006). Justice is a wide field, and as Rawls (1999) has rightly observed:

> Justice is the first virtue of social institutions, as truth is of system of thought. A theory however elegant and economical must be rejected or revised if it is untrue; likewise laws and institutions no matter how efficient and well-arranged must be reformed or abolished if they are unjust.

Among the ethical principles that inform science and technology policy, justice is therefore likely to play a major role, given its supremacy as a virtue of social rules and institutions. Articles 47 to 50 of the EU Charter deal with justice: they include the right to a fair trial, the right to be presumed innocent and the right to proportionate punishment. These rights have no direct relevance to science and technology policy; however, it has to be noted that the charter does not use the full scope of the justice principle, but is restricted to corrective and retributive justice. These are two of four distinct justice subprinciples that philosophers traditionally distinguish.

Of the subprinciples set out in Table 5.1, distributive justice could be especially relevant to science and technology policy. For instance, 'nano-divide' describes a concern that the gap between the rich and the poor, both within nation states and globally, will increase through the use of advanced technologies (Barakat and Jiao 2010):

> If global economic progress in producing high-value products and services depends upon exploiting scientific knowledge, the high entry price for new procedures and skills (for example, in the medical domain) is very likely to exacerbate existing divisions between rich and poor (Royal Society and Royal Academy of Engineering 2004, p. 52).

While such concerns can be grouped under 'distributive justice' as a subprinciple of justice, they can also be seen as relevant to the principles of solidarity or equality.

5.4.2 Solidarity

'Solidarity' means mutual support, especially among individuals with common interests. Solidarity is not as complex and long-debated a principle as justice. In fact, it does not even appear in Aristotle's work, nor in Immanuel Kant's.

Table 5.1 Justice

Justice subprinciple	Description
Justice in exchange	Establishes the fairness or equity of transactions
Distributive justice	Deals with the division of existing, scarce resources amongst qualifying recipients
Corrective justice	Rights a wrong that one has brought upon another, usually through a court declaring a remedy to correct the given injustice
Retributive justice	Establishes which punishment is appropriate for any given crime

However, it has become a much debated topic in bioethics, with some arguing that solidarity is a value that characterizes continental European welfare states as opposed to Anglo-American states, which rather focus on individual autonomy (Habermas 2003; Bayertz 1998; Hermerén 2008). As a group of Dutch researchers put it (Hoedemaekers et al. 2007):

> In a number of European welfare states altruistic solidarity as a commitment to help or support the needy and disadvantaged has been incorporated in their institutions and law. We term this institutional solidarity.

This institutional solidarity for the needy and disadvantaged is also part of the EU Charter, in Art. 27 to 38. While these articles also deal with workers' rights, the main emphasis is on access to social security and (preventive) health care for all. How is this value relevant to science and technology policy?

An example: it has been argued that large-scale genetic research should be governed by the value of solidarity rather than the value of autonomy. Chadwick and Berg (2001) believe that medical progress depends on research participants' accepting it as their duty to participate in research for the benefit of others Their use of the principle of solidarity focuses on *duties*, while the EU Charter focuses on *rights*. It is clear that such a duty-based use of the principle could have considerable implications for research and development, especially the recruitment of research participants or sample donors in medical research. At the same time, extended globally, the principle could be used to lobby for capacity building and technology transfer in the context of the nano-divide referred to above.

It is worth noting, though, that the solidarity principle as used in the EU Charter does not extend to international aid beyond the EU member states. Hence, global solidarity is not covered. Here one would have to look at global legal instruments such as the UN International Covenant on Economic, Social and Cultural Rights, which calls for international aid to achieve access to health care for all human beings based on the premise of the Universal Declaration of Human Rights that all human beings are born equal.

5.4.3 Equality

Only in logic is the principle of equality straightforward: two items or entities that cannot be distinguished are equal. In ethics and political theory, equality is not as easily described. Rather than referring to identical entities, the moral value of equality refers to equal *rights*, equal *opportunities* and equal *moral status.* It is only in this regard that we are all equal. The rights pronounced in the EU Charter are a good example: Arts. 20 to 27 are based on the understanding that nobody should be discriminated against, because we are all born equal in rights.

Difficulties arise not so much in the legal attribution of rights, but in political action. What does it mean *in practice* to have equal rights? In the *Nicomachean Ethics*, Aristotle referred to the formal equality principle, the principle of non-discrimination (1985). According to Aristotle, it does not matter whether a good man

steals from a bad man, or a good man rather than a bad man commits adultery: only the action counts. Hence, a court would have to ensure corrective and retributive justice for the bad man *and* the good man in order to preserve legal equality.

Yet even among philosophers who promote egalitarian policies, the principle is not clear. There are four interpretations of what equality means when linked to public policies: equality of wellbeing, resources, opportunity and capabilities (Daniels 1990).

Equal concern for the *wellbeing* of citizens is outcome-focused and tries to achieve equal welfare or at least equal preference satisfaction for all. This approach does not imply equal treatment, given that some citizens will require more support to achieve wellbeing than others (for instance, those with serious disabilities).

This account of equality puts responsibility for citizen welfare onto the government. Equality of resources, on the other hand, moves responsibility for welfare onto individual citizens, provided they are given access to resources. It is then left to them to convert these into wellbeing. Likewise, on the policy of equality of opportunity citizens are provided with the means to obtain certain ends for which they have to strive themselves. For instance, equal opportunity policies will provide education to all so that not only the wealthy acquire the skills and knowledge necessary to find satisfying jobs. The capabilities approach to equality aims to lift all human beings up to a given benchmark of functioning that allows them to pursue alternative life plans freely chosen.

What is important in all discussions of equality is to be aware of the privileges and restrictions ingrained in all societies, for instance the privileges that men enjoy versus women in terms of realizing life plans, or the privileges enjoyed by most in affluent versus lower income countries. As 'The World's Greatest Money Maker' (BBC 2009), Warren Buffett, has noted, 'If you stick me down in the middle of Bangladesh or Peru, you'll find out how much this talent is going to produce in the wrong kind of soil' (Singer 2009).

5.4.4 Dignity

None of the six values from the EU Charter is as contested, in either scholarly or policy debates, as that of dignity. The principle has been described as useless (Macklin 2003), arbitrary (Van Steendam et al. 2006), elusive (Ullrich 2003), groundless (Rachels 1990), a nebulous drug (Wetz 2004) and without reference point (Statman 2000). In fact, the Canadian Supreme Court decided in 2008 that dignity was not to be used in anti-discrimination cases any longer as it was 'confusing and difficult to apply'.[2] At the same time, dignity is a principle evoked in almost all modern constitutions and human rights treaties.

Articles 1 to 5 of the EU Charter summarize dignity rights, which include the right to life and integrity of the person, the prohibition of torture and inhuman or degrading treatment, and the prohibition of slavery and forced labour.

[2] *R. v Kapp [2008] Supreme Court Canada 41* at §22: '[H]uman dignity is an abstract and subjective notion that… cannot only become confusing and difficult to apply; it has also proven to be an additional burden on equality claimants, rather than the philosophical enhancement it was intended to be.'

An example of the complexity and difficulty of interpreting what the principle of dignity means can be given in the context of nanotechnology. When the European Group on Ethics in Science and New Technologies (EGE) identified the ethical questions relating to the development of nanomedicine, its first question was: 'How should the dignity of people participating in nanomedicine research trials be respected?' (EGE 2007). If one links this back to the dignity rights in the EU Charter, one wonders which right could be violated by taking part in nanomedicine research trials. Certainly not the prohibition against torture or slavery. The right to life? But then safety concerns are usually discussed outside of dignity debates. The right to integrity of the person? The further explications of this right given in Art. 3(2) of the charter are:

In the fields of medicine and biology, the following must be respected in particular:

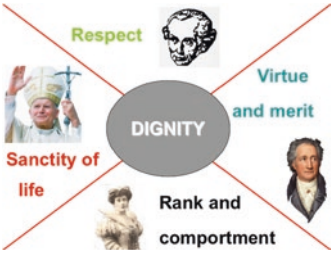
- the free and informed consent of the person concerned, according to the procedures laid down by law,
- the prohibition of eugenic practices, in particular those aiming at the selection of persons,
- the prohibition on making the human body and its parts as such a source of financial gain,
- the prohibition of the reproductive cloning of human beings.

Looking at the above, it is still not possible to link the dignity concern of the EGE to the explicated rights. The reason could be that the concept is used in widely different ways: 'dignity' can serve, for example, as a synonym for religious principles or in a comment on a person's manners. Figure 5.2 demonstrates the principle's breadth of application by coupling definitions of common understandings of dignity with illustrative quotations (Schroeder 2008, 2010).

Looking at this range of dignity concepts, it is not surprising that the Canadian Supreme Court decided that dignity was too confusing and difficult to apply in its decisions. However, the principle plays a supreme role in most constitutions,

'A human being … possesses a dignity (an absolute inner worth) by which he exacts respect for himself from all other beings in the world' (Kant 1996).

'[T]he Gospel of the dignity of the person and the Gospel of life are a single and indivisible Gospel' (John Paul II 1995).



'A wreath is much easier bound than a dignified head for it found' (my translation: In the original German: 'Ein Kranz ist gar viel leichter binden, als ihm ein würdig Haupt zu finden) (Goethe n.d.)

'Conducting a public romance may have reduced the dignity of the presidency, but Sarkozy is president for an era in which dignity is less important than humanity' (Tharoor 2008).

Fig. 5.2 Meanings of dignity

and any attempt at purging such a powerful concept from ethical discourse would amount to whistling in the wind, in the view of some legal scholars (Beyleveld and Brownsword 2001).

5.4.5 Citizens' Rights

Articles 39 to 46 describe very specific citizens' rights, ranging from the right to vote in European elections to the entitlement to diplomatic support when travelling abroad. Given that the whole charter consists of citizens' rights, it is somewhat surprising that the drafters chose these terms. Aside from that, however, what is of some interest here is the concept of a right in itself, in particular given current debates about the differences between Western and Asian ethical systems.

It has been argued that the Asian approach to ethics is community-based, focusing on the recognition of the interdependence of all forms of life on earth. It thereby presents 'holistic harmony' as an essential feature of its ethics (Sakamoto 1999). Likewise, in traditional Chinese society, 'there is less emphasis on individual rights, self-expression, and self-determination. In the community, qualities such as harmony, function, and responsibility are stressed more than individual rights, and familial relationships assume primary importance' (Ip et al. 1998).

What, then, is a right? Human communities are organized by social rules, many of which are encoded in law and administered through courts. These rules can be rights-centred or obligation-centred. As early as 1861, John Stuart Mill defined rights in a way that is still valid today (Mill 2002):

> When we call anything a person's right, we mean that he has a valid claim on society to protect him in the possession of it, either by the force of law, or by that of education and opinion … To have a right, then, is … to have something which society ought to defend me in the possession of.

A right as understood in the EU Charter is therefore a claim that individual EU citizens have on EU bodies. This claim right is open to each one of the approximately 500 million people living under EU law. It is centred on the individual, not on the community he or she lives in. In the context of science and technology, the rights of individuals can be usefully illustrated by way of the field of research ethics in medical research.

To achieve progress in medical research, experiments on human beings are necessary. Research ethics is the field that governs how such research must be conducted if it is to respect fundamental human rights. These rights are non-negotiable and cannot be overridden by reference to, for example, the common good. Hence, no human being can be involved in research against his or her will. Individual rights take precedence over the good of the community in medical research. Article 8 of the World Medical Association Declaration of Helsinki reads (WMA 1964):

> While the primary purpose of medical research is to generate new knowledge, this goal can never take precedence over the rights and interests of individual research subjects.

5.4.6 Freedoms

Rights and freedoms are closely linked concepts. Western philosophers usually distinguish negative freedom from positive freedom. 'Negative freedom' describes the absence of barriers or external restraint, while 'positive freedom' describes the powers and resources required to pursue one's life plans (Berlin and Hardy 2002). To be able to move to a different country as a privileged academic is a negative freedom, in that nobody stops us from going and no immigration control stops us from entering. However, this same ability would be a positive freedom for an orphaned child rescued in a war zone and taken abroad for hospital treatment or perhaps to stay.

The freedoms given to EU citizens through the charter include broad negative rights such as the right to property (Art. 17) and the right to liberty (Art. 6), as well as more specific negative rights such as the right to marry (Art. 9) and the right to religious freedom (Art. 10). On the other hand, the right to education (Art. 15) is a positive freedom as it provides resources for individual citizens in order to increase their choices in life.

Strict libertarians argue that the state should be minimalist and focus on protecting negative freedom only (Nozick 1974). However, it is one of the defining features of Europe, especially continental Europe, that positive freedoms are given prominence. This approach can be observed, for instance, in the European Commission's action plan on nanosciences and nanotechnologies. Rather than focusing on the negative freedom of researchers to 'choose an occupation and right to engage in work' (Art. 15), the plan focuses on the positive freedom of the public 'to establish an effective dialogue with all stakeholders' (European Commission 2005) and to take people's expectations and concerns into account.

5.4.7 Sustainability

The values discussed so far are about people; sustainability is about the environment. Yet some approaches to environmental protection and sustainable development are highly people-focused or instrumental (Fox 1996).

Instrumental approaches to the environment value the environment only in so far as it is useful for or appreciated by humans. In this regard, concern for the environment is only indirect, mediated through a direct moral concern for other people. The different instrumental approaches are set out in Table 5.2.

In contrast with instrumental approaches, intrinsic value approaches to the environment accept that the environment, independent of humans, has a value in its own right. Hence, the concern for the environment is direct. This is set out in Table 5.3.

The emphasis in the Treaty of Lisbon on sustainable *development* and the promotion of *scientific and technological advancement* (Art. 3(3)) suggests that the European Union's stance on sustainability and environment is instrumental, in

Table 5.2 Instrumental approaches to the environment

Term	Approach
Expansionism	The environment is valued instrumentally for its contribution to economic growth and there are no limits to such growth
Conservation	The environment is valued instrumentally for resources required in farming, mining, logging etc., and it needs to be conserved for future use
Preservation	The environment is valued instrumentally for contributions to human wellbeing (e.g. it is good for physical recreation or a potential source of new medicines) and ought to be preserved, including for future generations. By contrast with conservation, which focuses on use value, preservation focuses on keeping the environment from harm, including unrestrained economic exploitation

Table 5.3 Intrinsic value approaches to the environment

Term	Approach
Sentience	Entities are intrinsically valuable if they are sentient. This is also called the animal liberation approach, and its most famous proponents are Bentham (1996) and Singer (1995)
Life	Entities are intrinsically valuable if they exhibit a biologically based 'interest' in maintaining their own integrity—put simply, if they strive to maintain their own existence (e.g. a plant will expand its roots until it can reach water)
Holistic integrity	Entities are intrinsically valuable if they have self-renewing properties as a whole, i.e. if they are autopoietic systems such as ecosystems. The most famous proponent of this approach is Leopold (1980)

other words people-centred or anthropocentric. The environment is to be protected and preserved in order to enable the sustainable use and continued availability of valuable resources for the benefit of today's and tomorrow's humans.

5.5 Case Study: Preimplantation Genetic Diagnosis in Europe

The far-reaching collaboration necessary to form a union of 28 countries has been accompanied by the transfer of national competences to EU institutions and, as we have seen above, by the codification of shared values. One can find striking consensus on certain applications of science and technology, such as the shared rejection of eugenic practices and reproductive cloning of human beings, both deemed to be in violation of human dignity, according to Art. 3(2) of the Charter of Fundamental Rights. However, the European Union is still a constellation of more than two dozen member states, each with its own distinct cultures and values, which also apply to its approach to science and technology and the applications thereof. In the light of such differences, it is important to keep in mind that in spite of the far-reaching collaborative nature of the EU, member states still have considerable autonomy in some areas. In fact, the competences of the EU itself are strictly limited to those conferred upon it by its member states (Art. 5(1) and

(2) Treaty on European Union). This section of the chapter examines differences in the understanding of values by way of a case study on preimplantation genetic diagnosis (PGD).

5.5.1 Preimplantation Genetic Diagnosis

What is PGD? The Health Council of the Netherlands defines it as 'the examination in vitro of an embryo (or an egg cell prior to fertilisation) in order to exclude a genetic condition in case a very high risk of that condition is known' (Health Council of the Netherlands 2006). Since PGD takes place prior to transfer to the womb, it can only be used in combination with in vitro fertilization (IVF). PGD is most commonly used by prospective parents who are carriers of (severe) hereditary diseases, such as Duchenne muscular dystrophy or sickle cell disease (Health Council of the Netherlands 2006). By using PGD, parents aim to ensure that only unaffected embryos are transferred to the womb. PGD is considered ethically controversial in several regards:

- The life and moral status of the embryo are not respected by PGD.
- IVF and PGD are too burdensome for women.
- PGD leads onto a slippery slope towards 'designer babies'.
- PGD can detect genes for diseases that may never develop (e.g. BRCA1 and BRCA2 mutations that predispose respectively for breast cancer and ovarian cancer).
- 'Saviour siblings'[3] are instrumentalized and treated as a commodity.
- PGD can be used for non-medical sex selection, a practice quite common in the United States (Dondorp and De Wert 2005; Health Council of the Netherlands 2006; De Wert 2005; Pennings and De Wert 2003; Brownsword 2005).

The next section briefly examines how PGD is governed in the United Kingdom, the Netherlands and Germany.

5.5.2 PGD in the United Kingdom

The United Kingdom has a long history of assisted reproduction. The first baby ever to be conceived via IVF was born there in 1978. This event and the rapid speed of developments in assisted reproduction led to the establishment of a national committee to develop principles for the regulation of IVF and embryology. The committee, chaired by philosopher Mary Warnock, concluded in its 1984 report that the human embryo should be protected, but research on embryos and IVF was permissible as long as appropriate safeguards were respected (Warnock 1984).

[3] A child born specifically in order to secure the health of an older sibling, for instance to provide matching tissue for a bone marrow transplant.

In the United Kingdom, PGD is allowed as long as the Human Fertilisation and Embryology Authority agrees that the condition the parents could pass on to the child is sufficiently severe. To this end, the authority has published a list of the conditions it has approved so far. The list is quite extensive, and includes BRCA1 and BRCA2 mutations, which predispose to breast and ovarian cancer (HFEA 2014). PGD for human leukocyte antigen (HLA) typing as required for 'saviour siblings' is allowed, but such tests are licensed case by case (HFEA 2014). By contrast, sex selection for non-medical reasons is not allowed in the United Kingdom, in terms of the Human Fertilisation and Embryology Act of 1990. Overall, the United Kingdom has a rather *liberal* approach to the application of PGD.

5.5.3 PGD in the Netherlands

In the Netherlands PGD is allowed for the screening of severe hereditary diseases. The permitted scope of screening is determined by the 'Ministerial regulation of pre-implantation genetic diagnosis' (Aarden et al. 2009), which is based on the Embryo Act (*Embryowet*) of 2002. Whether or not PGD will be allowed is determined case by case by the performing clinic. To comply with the Act, the clinic has to consider the following criteria listed in the regulation:

- the severity and nature of the disease,
- treatment possibilities,
- additional medical criteria (e.g. whether or not expression of the condition at hand could be prevented) and
- psychological and moral factors.

The Dutch cabinet intended to allow PGD for prospective parents who were carriers of (severe) hereditary diseases with a high likelihood that the disease would be contracted by the child. After an intense parliamentary debate in 2008, the scope of permissible PGD was expanded to include hereditary conditions, even where they might never present as a (severe) disease. The regulation specifically mentions the BRCA1 and BRCA2 genes as examples. PGD for HLA typing is, however, explicitly banned in the Dutch regulation, in contrast to the United Kingdom, as the 'new child' would only be conceived to benefit another child. In the Netherlands, as in the United Kingdom, sex selection is strictly limited: there must be medical reasons, according to Art. 26 of the Embryo Act. One might say that the Netherlands has a *moderately tolerant* stance towards PGD.

5.5.4 PGD in Germany

Until 2010, PGD was banned in Germany. In particular, the German Embryo Protection Act (*Embryonenschutzgesetz*) of 1990 prohibited any use of human embryos created in vitro that did not serve the embryo's preservation and

the establishment of a pregnancy. Although the Act did not explicitly mention PGD, several articles were interpreted by academics and policymakers as forbidding the technology (Aarden et al. 2009). In July 2010, however, the German Supreme Court (*Bundesgerichtshof*) ruled that the Embryo Protection Act did not establish a ban on PGD. This in turn led to major public and political discussion (Deutscher Bundestag 2011).

In December 2011, after an intense political debate, PGD was eventually allowed under strict conditions, when the Preimplantation Diagnosis Act (*Präimplantationsdiagnostikgesetz*) came into force. According to the Act, PGD is prohibited in principle, but can be allowed if exceptional conditions are met, for instance case-by-case approval by an interdisciplinary ethics commission combined with extensive counselling of the prospective parents. More importantly, PGD is limited to (severe) conditions that are highly likely to lead to miscarriage or the death of the infant within the first year. This effectively prohibits PGD for HLA typing, for the screening of hereditary conditions that might not develop into a disease (e.g. BRCA1 breast cancer) or for sex selection for non-medical reasons (Deutscher Bundestag 2011). As a result, one can characterize Germany as being *restrictive* towards PGD.

5.5.5 *Comparing PGD Dispensations in Europe*

Comparing the three EU member states examined above, one sees two commonalities. First, all three allow PGD in screening for acute life-threatening conditions, and second, they prohibit sex selection for non-medical reasons. However, if we look at other (contested) applications of PGD, we see notable differences (Table 5.4).

Values are a decisive factor in regulatory choices made regarding PGD in the three countries. The United Kingdom, the Netherlands and Germany, which all fall under the EU Charter of Fundamental Rights, have considerable room to develop policies to govern contested science and technology applications.

Table 5.4 Preimplantation genetic diagnosis in the United Kingdom, the Netherlands and Germany

PGD applications	 United Kingdom	 The Netherlands	 Germany
Sex selection for non-medical reasons	Prohibited	Prohibited	Prohibited
HLA matching (‘saviour siblings’)	Allowed	Prohibited	Prohibited
Cancer predisposition (e.g. BRCA1)	Allowed	Allowed	Prohibited
Acute life-threatening conditions	Allowed	Allowed	Allowed

5.6 Conclusion

The principles and values recognized by the Charter of Fundamental Rights of the EU and the Treaty of Lisbon constitute the point of reference for all acts by bodies of the EU. Hence, they also apply to science and technology policies and guidelines.

The EU thus conforms to a human rights framework and culture that prioritizes non-negotiable individual human rights over the common good. As the case of PGD has shown, member states retain considerable autonomy to develop independent policies to govern contested science and technology applications, an autonomy that is justified through the subsidiarity principle of the charter. However, this principle is most certainly not unproblematic, since the autonomy of each member state extends beyond its own citizens, due to the free movement of persons and of services that is a core freedom of the EU in terms of Art. 26(2) of the Treaty on the Functioning of the European Union (EU 2008). EU citizens of restrictive member states can easily travel to more liberal countries to make use of controversial technologies. Belgium, for instance, has a more liberal policy on PGD (comparable to the regulations in the United Kingdom) than its neighbour Germany (see, for instance, Centrum voor Reproductieve Geneeskunde n.d.).[4] According to a study by Leopoldina (the German National Academy of Sciences) PGD is carried out for around a hundred German couples every year in one Belgian centre alone (Leopoldina 2011). Regulating reproductive tourism is just one unresolved instance of uniting differing value systems in the far-reaching collaboration of the EU. Given that science and technology developments occur at rapid speed, such regulation will certainly remain a challenge within the union.

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[4] See for instance: http://www.brusselsivf.be/genetic-diagnosis-embryo (In English).

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