

# Respect for Autonomy and Technological Risks

**Lotte Asveld**

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# Respect for Autonomy and Technological Risks

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# 1 Autonomy in a technological World: why we need a better approach

## 1.1. Contested technologies

In recent years, Sports Utility Vehicles (SUVs) have gained popularity in both Europe and the US for their robust appearance, their spaciousness and the sense of safety they convey; for some car loving individuals, a SUV represents the ultimate driving experience, possibly surpassed only by a Hummer, which is even larger. However, for many other people, the SUV represents a package of unnecessary dangers and annoyances, owned by selfish, anti-social individuals. They perceive a SUV to be extra harmful to other road users and a threat to the environment.

For someone owning a SUV, the car probably symbolizes a high degree of personal autonomy. A SUV allows the owner to go where-ever she likes, as most SUV are designed to cover all kinds of terrain, in a comfortable way. The heightened driver's position is attractive and most drivers feel safe in a SUV.

For other people, the increased number of SUVs may actually diminish their sense of personal autonomy: they are confronted with cars that double the chance of a fatal outcome in an accident involving a pedestrian (see Lefler & Gabler: 2004). Additionally, the sense of safety conveyed by the robustness of SUVs leads drivers to drive less carefully (see Thomas & Waldon: 2007). SUVs furthermore use considerably more gasoline than other vehicles, which makes them a heavy burden on the environment. Until now, there is not much individuals can do to curb the increased use of SUV's, although some have taken it upon themselves to destroy SUV's, i.e. 'Earth Liberation Front', while others have opted for a less violent approach through awareness-campaigns: 'What would Jesus Drive?'

Technological developments can offer substantive benefits, while the associated risks can prove to be heavy burdens. Whether one thinks the benefits outweigh the burdens is to a large extent determined by one's larger system of beliefs and values. People who for instance do not regard global warming to be a



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serious problem - either because they consider it to be non-existent, or because they expect that global warming will be beneficial - will have fewer problems with the high CO<sub>2</sub>-emissions of SUVs than people who do worry about global warming and related environmental problems. Another relevant consideration with respect to the acceptability of SUVs is how one interprets the value of freedom. Does freedom imply that one can drive any car one desires? Or does it imply that one has a direct responsibility for the natural environment?

The main question guiding this research is: How should we decide about the acceptability of technological risks, given the divergence in individuals' beliefs and values? The main premise of this dissertation is that in formulating answers to questions about the acceptability of technological developments and the associated risks, the value of respect for autonomy is of paramount importance. Autonomy is one's capacity to make and act upon choices according to one's own moral framework and associated belief system. Autonomy is a cornerstone of liberal, democratic societies and it is a value that is worth cherishing because it is fundamental for the political, cultural and economic achievements citizens in, mostly western, societies enjoy at present.

Faced with an increasing rate of technological innovations, the question of how individual autonomy can be preserved becomes ever more pressing. Although it might be said that technological developments actually support individual autonomy, the incidence of technological risks raises problems with this assumed positive correlation. The value of respect for autonomy implies that if I deem a technology unacceptable because of the associated risks, then I should not have to tolerate it in my environment. Currently the individual has only limited options to influence decisions on the acceptability of technological risks. This can be improved as will be shown in this research.

What complicates the question about individual autonomy in relation to technology is the collective character of technological applications. Technological developments usually concern a larger group of people, not just one individual. This contrasts with medical practice, where respect for autonomy has also been identified as a central value. In this context, respect for autonomy has been accommodated by introducing the procedure of informed consent (IC). This is a process in which the physician informs a patient about the risks and benefits associated with a proposed treatment, and then the patient is expected, on the basis of this information, to consent or not, to under go the treatment given the known, associated risks (see Faden & Beauchamp: 1986). Some authors (see

Martin & Schinzinger: 1983) have proposed that this principle should be introduced in technological practice to tackle the issue of respect for autonomy. I will discuss the differences between medical and technological practice more extensively in the next chapter and consider the appropriateness of using IC for technological practice.

One of the main reasons why the introduction of IC is problematic in technological practice is that isolated dissent or assent of a single individual will not suffice to accommodate autonomy. SUV-drivers obviously consent to the risks associated with the use of SUVs while members of the Earth Liberation Front obviously dissent. Solely considering their respective positions will not suffice to respect the autonomy of both groups. The most important question to ask is therefore how collective decision procedures around the acceptability of risks should be designed to optimally accommodate individual autonomy. Such decision procedures should lead to outcomes that take the different perspectives into account. The current decision procedures designed for this task are lacking when it comes to accommodating the autonomy of all participants involved. These decision procedures include liberal representative democracy, the market and participatory technology assessment (PTA). This latter instrument was developed in a response to deficits identified in the first two instruments. Let us now take a closer look at the problems arising with these procedures.

### **1.2. Decision procedures on the acceptability of technological risks**

#### **1.2.1. Liberal representative democracy**

Why is liberal representative democracy ineffective with respect to the value of autonomy and technological risks? It can be said that liberal democracy was originally intended to promote individual autonomy. It gives the individual a voice, a vote in political matters while protecting certain essential liberties, such as freedom of speech. The principle of liberal democracy, interpreted as popular rule with respect for specific individual liberties therefore reflects respect for autonomy. In the field of the acceptability of technological risks however, there is still much room for enhanced opportunities for autonomous decision-making of individuals on political matters.

Liberal democracy is basically a precarious balance between the self-determination of individuals and the power vested in governments to further

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common interests (see Held: 1996). This power is given to the government by individual citizens through their votes, these votes are an expression of trust, a trust that the government representatives will do their utmost to protect the interests of the citizens. This implies that such representatives do not need to ask permission from the public for each and every decision they make. Moreover, the representatives are not expected to protect particular interests, they are expected to take into account all the different interests present in a society and to find the best ways possible to protect these interests. Seeking consent from citizens each time a decision is made that might serve collective interests in long-term but is hard to swallow in the short run, would render the tasks of representatives impossible. Therefore, voting is a way to express ones consent over a period of time to the general political course that a group of representatives takes.

It has been argued that periodic elections, as are common in most western liberal democracies, offer only a very meager instrument for citizens to use to control their governments (see Barber: 1984; Sclove: 1995). Indeed, a single vote to express one's opinion on a wide variety of issues can hardly be considered an adequate way to communicate one's preferences effectively.

Voting is not the only available means for citizens to influence policy-makers and governmental representatives. There are many other ways such as public demonstrations and influence via trade-unions and other organized interest groups. As Mark Brown (2006) puts it: 'Democratic representation depends on continuous interaction between decision-making in state-institutions and various sorts of public talk, including both informal public discourse and the more structured forms of deliberation that occur in civil society.' (p. 206). Moreover, he adds, democratic representation is not supposed to be a one-way process. Representatives can be expected to be constantly engaged with their constituency, even with those that are unorganized, such as the underprivileged (see Brown: 2006, 206).

Yet, with regard to technological risks, the options for individual laypeople to influence democratic decision procedures are restricted (see Sclove: 2000), in this field, a division is maintained between experts and laypeople. The acceptability of risks is usually decided by using scientific risk assessment. These assessments consist of three stages: identification of risk, i.e.: What might possibly constitute a risk?, estimation of risk, i.e.: What is the magnitude of the risk, and evaluation of risk, i.e.: Is the risk acceptable? This last stage is usually

decided using political decision procedures. The outcome of the last stage depends considerably on the input from the first two stages.

Dealing with the, possible, input of laypeople in each of these three stages of risk assessment is generally regarded as problematic because technological developments are often highly complex, this implies that assessing risks properly requires a high degree of specialist knowledge (see Kleinman: 2000; Shrader-Frechette: 1991, ch.7). Today, now that we have a number of cases where laypeople did get involved in risk assessment, it has become clear that this assumption is untenable (see Kluver *et al.*: 2000; Shrader-Frechette: 1991b; Kaplan: 2000; Hassanein: 2000; Wynne: 1996a). As Kluver *et al.* note (2000, ch.2), the exclusion of laypeople from the risk assessment process can harm the quality of the decisions made regarding the acceptability of risks for two main reasons.

One, laypeople may provide valuable information as to which developments can be identified as risks and what kind of harmful consequences they might entail. Laypeople often have detailed knowledge of their own environment and can detect unusual occurrences quickly (see Kleinman: 2000, 146). Experts may not always know under which circumstances technologies are applied or how certain artefacts interact with local practices and geographical peculiarities. The non-scientific knowledge laypeople provide may prove indispensable for the quality of scientific knowledge (see Wynne: 1996a). Excluding information from laypeople from risk assessments can be termed the cognitive defect of current decision procedures for determining technological risks (see Kluver *et al.*: 2000).

Two, the inclusion of laypeople in decision procedures designed to determine the acceptability of risks will increase the legitimacy of the final decision; it increases the probability that all moral perspectives are taken into account, thereby enhancing the acceptability of the decision to a larger part of a society than would be the case if laypeople were excluded from the decision. The inclusion of various moral perspectives is most pressing in the third stage of risk assessment when a risk is evaluated. However, moral perspectives may also impact on the first two stages of risk assessment as will be explained in the following chapter.

I believe that the above mentioned defects are more pressing in relation to technological risks than other areas of political life because of the supposed divide between input from experts and input from laypeople. It is reasonable to treat scientific input and non-scientific input as different kinds of input

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according to different standards, as will be done in this dissertation. However, that does not imply that the perspectives of laypeople should be completely excluded as sometimes happens in decisions on the acceptability of risks. Especially since 'acceptability' implies that more than risk assessment is needed, such as moral considerations. These considerations figure explicitly in laypeople's conception of risk (see Roeser: 2006).

This identified divide between experts and laypeople appears to be much less common in other types of political decisions. When it comes to cultural integration, education or social security, the opinion of laypeople seems to be valued more strongly than in matters of technological risk. This can partly be explained by the fact that laypeople feel less qualified to comment on questions regarding the acceptability of technological risks than in other political areas, possibly as a reflection of the attitudes of experts and policymakers.

In the other policy-areas mentioned above, laypeople and experts alike may consider the divide between qualified and unqualified commentators less prominent because these issues require less dedicated knowledge. Everyone in a modern western society has some relevant experience in the area of education, cultural integration and social security which enables one to contribute to a public debate on such issues. The particular problems involved in these areas may additionally be understood as strictly moral problems, opposed to the scientifically framed problems in the field of technological risks. Formulating an acceptable approach to moral problems is commonly assumed not to require specialist knowledge. In moral issues, everybody is potentially an expert, whereas for questions involving technical matters, expertise is defined within strict boundaries. This hampers the inclusion of various perspectives in risk assessment and hence undermines respect for autonomy in liberal democratic decision procedures with regard to technological risks.<sup>1</sup>

According to classical liberal theory, democracies serve the self-determinacy of individuals through two principles: representation and a free market system (see Held: 1996; 104). Assuming that representation is in principle an effective instrument for protecting the common interests of individuals, it should be considered defective in respecting autonomy with regard to technological risks as organized at present. For democratic representation to be effective at the level

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<sup>1</sup> I do not mean to say that *all* perspectives should necessarily impact on the decision made. Later in this dissertation I will argue for a distinction between tenable and untenable perspectives on risk.

of technological risks, it needs, at minimum, to take into account the various perspectives and interests of the people who are represented. As described above however, it is often the case that the perspectives of laypeople on the acceptability of risks are not taken into account, while there are sufficient reasons to believe that their input would contribute to the quality of the decision made. We will now consider whether a free market system can be expected to contribute to individual autonomy with regard to technological risks.

### 1.2.2. Market

Market mechanisms are typically tailored to suit the preferences of the individual, the idea behind this is that as long as the individual has substantial freedom of choice, the market can provide for each individual according to his or her needs (see Friedman: 1962). Producers will be concerned about the preferences of their customers in order to survive at all: if people want to eat tomatoes engineered to taste like blueberries, then it will be marketed by a provider who grasps the opportunity.

Market mechanisms cannot be considered adequate instruments that can be used to assure individual autonomy with regard to technological risks for two reasons: one, the problem of negative externalities and two, the problem of preference distortion. Externalities are the consequences of an action that affect other parties, while these consequences are not reflected in the market price, for example the air polluting effects of air travel. Whether one travels by plane or not, one is confronted with the air pollution that results from this mode of transportation. Preference distortions is the term I use to cover the fact that if an individual buys a certain product, it does not necessarily imply that she thinks the risks associated with the product are acceptable. I will elaborate on these two concepts below.

Market externalities occur when the costs, or benefits, to individuals that do not participate in a transaction are not incorporated in that transaction (see Cornes & Sandler: 1996). Such costs may, for instance, arise during the production process of a product. I cannot prevent genetically modified (GM) crops from being planted by solely consuming genetically modified organisms (GMO) free food. Thereby, I cannot avoid all the risks I associate with GM-food, such as the ecological harm GM-crops might do to the environment, or the economic threats associated with the patenting of gene constructs that enables

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the genetic modification of crops. The preferences of a person rejecting GMOs are not included in the transaction between a consumer of GMOs and a producer of GMOs. The burdens of the imposition of a perceived risk are external to the transaction. In such a case, the individual who rejects GMOs because of the associated risks is devoid of opportunities to influence the decision with regard to the acceptability of these risks and hence is undermined in her autonomy.

Several solutions exist to deal with the problem of externalities, but it appears to be a rather persistent phenomenon. When it comes to environmental degradation, into which many technological risks can be categorized, one solution is to privatize natural resources, so that a specific party benefits from protecting this resource and hence has a vested interest in doing so. This is a workable solution with, for instance, lakes and wildlife reserves. However, with other natural resources such as air or seawater, such an approach is less suitable because it is difficult to limit access to these resources and hence to charge 'consumers' of those resources (see Cowen: 2007). Another option is to force producers to internalize the burdens associated with some of their products, such as environmental degradation, however, it can be difficult to establish the value of such negative externalities as nobody is buying them. For such cases, government intervention may be more appropriate but this brings us back to the issues discussed above.

The other reason why market mechanisms do not suffice to bring about respect for individual autonomy is the problem of preference distortions. It might be stated that if most people buy GMO-food then this might indicate that most people agree with the (alleged) risk involved in this production method. However, this idea is refutable.

People do not always purchase items according to their preferences about risks. Consumer's behavior is influenced by many factors that shape their available options. Many of the choices offered to us are the results of social-economic mechanisms and institutions that predate production (see Peter: 2004). Organic, GM-free food for instance is usually more expensive and harder to come by than conventional (GM-) food. This is a result partly of subsidy-policies. In the current situation, organic food is more expensive than conventional (GM-) foods. This could be altered by subsidizing organic food for instance because it is more environmentally friendly. At present, if people are on

a tight budget, they have little opportunity to buy organic food partly because of political instruments that are beyond the control of individual consumers.

Therefore, market mechanisms cannot be considered adequate instruments to manage respect for individual autonomy. The political decisions that influence the market should be open for deliberation so that approaches can be formulated that take into account, as much as possible, the different perspectives of individuals on the acceptability of risks.

It might be objected that political decisions should never influence a market as this might lead to market distortions. A market that does not function properly as a market, but as a reflection of the preferences of a political elite, can not be expected to accommodate individual preferences adequately. This objection ignores the fact that, in specialized, modern societies, the market often necessarily reflects the preferences of a restricted group of people, such as designers and scientific risk-assessors. Conventional market mechanisms allow people merely an end-of-the-line choice. Individuals can only accept or reject a specific technology, while many choices that eventually shape a technology have already been made in the design process of the artefact or during the decision procedures leading to the relevant safety regulations (see Sclove: 2000, 39; Wynne: 1980). Such decisions relating to design or safety are not necessarily political, but they do impact the risks associated with a particular technology.

Both from a pragmatic and from a moral standpoint, it is preferable to include laypeople in the earlier stages of the design and regulation of a technology. It is preferable from a pragmatic perspective because this will contribute to a smooth dissemination of a new technology within society. It is preferable from a moral perspective because the opportunity to influence the design and regulation of a new technology enhances the individuals' ability to live autonomously. Efforts to include people in earlier stages of technological development have emerged in the form of PTA. How these procedures are carried out and how we should evaluate their contribution to individual autonomy will be discussed below.

### **1.2.3. Participatory Technology Assessment**

In 1987 the Danish Board of Technology organized the first ever consensus conference that included lay people, one of the first forms of participatory technology assessment (PTA). The topic of the conference was Gene-Technology



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in Industry and Agriculture. After this initial experiment, other European countries adapted the format to include lay people in decisions on technology-related issues. Biotechnology proved a popular subject in most European countries, followed by issues such as mobility, energy and privacy in an age of pervasive information technology (see Kluver *et al.*: 2000).

How much PTA contributes to respect for autonomy in relation to technological risks, depends on the specific format chosen. A wide variety of PTA formats exists, there are also a number of formats in the related field of participatory integrated assessment (PIA), which closely resembles PTA (see Turnhout & Leroy: 2004). PIA does not explicitly target technology, but may sometimes concern issues related to the assessment of technological risks, such as discussions about environment degradation. In this context, I will regard PTA as a subset of PIA as both may be used to discuss the acceptability of risks using comparable means. Where PIA is distinctly different from PTA, I will mention PIA separately.

The formats available for PTA vary along four axes. One is the axis of democratic vs. advisory purposes (see Asselt *et al.*: 2001). This axis refers to the impact the outcome of the PTA has on actual policy. When a PTA is organised for democratic purposes, the outcome of the PTA will have direct consequences for actual policy. However, most PTA-processes are of an advisory nature (see Kluver *et al.*: 2000, 38). This limits the influence a layperson can exert on decision procedures regarding technological risks and thereby it limits her autonomy.

The second axis consists of the opposition 'mapping diversity' vs. 'consensus achievement'. It refers to whether a PTA is aimed at reaching consensus, as in the case of a consensus conference, or whether a PTA is intended merely to make an inventory of the various perspectives on the topic under scrutiny, which is the case with focus groups, in which a small group of people is asked to discuss a specific topic. When consensus is achieved within a group, it becomes more likely that the outcome of the process will directly impact policy-making, hence strengthening the accommodation of individual autonomy. However, the effort to reach consensus may also smother the distinct perspective of the individual in the pressure to conform, thereby limiting the options to exercise individual autonomy.

The third axis constitutes the background of the participants. In some PTA-processes, such as consensus-conferences, participants consist mainly of

laypeople without any prior material interest in the subject (see Slove: 2000, 35). In other cases, the participants are exclusively experts or sometimes the participants are made up entirely of stake-holders with distinct prior material interests in the subject (see Van Asselt *et al.*: 2001). A motivation for selection is to avoid domination of the discussion by people who already have a strong opinion, such as professional activists. It is difficult to comment on this axis generally, but it may be stated here that the exclusion of laypeople with a strong prior interest in a specific matter, does not enhance their options for autonomous decision-making. In this research it will be argued that the value of respect for autonomy dictates that especially those people with strong prior interests in a specific matter should be included in the relevant decision procedures.

A fourth defining axis of PTA's relates to the framing of the motivating question. Often this is done by the organizing institution. This question can be more or less strictly defined. Some framing allows for further refinement by the participants, whereas in other cases, the question is firmly set beforehand, limiting the input of participants to responses to the main question (see Kluver *et al.*: 2000). Framing is an important matter when it comes to respect for autonomy. The framing of a question may lead to the exclusion of some perspectives or issues that are salient to some individuals, thereby limiting their options to bring forth their concerns about the topic under scrutiny and thus negating their autonomy.

The inventory of these axes given above conveys an impression of the wide-ranging possibilities of PTA. It would take too much space to discuss each of the axes extensively with respect to their contribution to respect for individual autonomy. Overall, they can be considered an improvement when compared to conventional decision procedures in which laypeople often have no voice. Nonetheless, overall they show little respect for individual autonomy. Most of the PTA and PIA-instruments maintain a division between experts and lay people when describing risks (see Turnhout & Leroy: 2004, 19; Kleinman: 2000). The input of laypeople is limited to an evaluation of the risks and is usually left out of the first two stages of a risk assessment: identification and estimation of risk. In most PTA-processes it is acknowledged that a variety of risk representations can be equally valid and that laypeople should be given the opportunity to make up their mind about which of these representations appeals to them most, but this is not the same as contributing directly to the way a risk is represented. It is

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argued in this research that all three stages of risk assessment should be open to input from laypeople. A first sketch of how this is envisioned will be given in the next section.

### 1.3. Amendments to existing decision procedures

The leading question for this research is: How can autonomy be respected in the context of technological risk? The answer to this question will consist of recommendations for amendments to existing decision procedures. As stated above, existing procedures are insufficient to accommodate autonomy and they require improvement on three main aspects, which I will discuss in turn.

#### 1.3.1. Criteria for evidence of harm

Firstly: all three stages of risk assessment: identification, estimation and evaluation are relevant when deciding on the acceptability of technological risk. In order to respect individual autonomy, all the three stages should be open for input from all kinds of people, with their diverging perspectives. This includes the representation of risks that follow from the first two stages. These representations are usually considered to be too complex for laypeople as they are scientifically framed. However, the representation of a risk strongly influences its acceptability. In respecting autonomy, it is important that the representation of risk reflects the different perspectives that exist with regard to that risk.

The claim put forward in this research is that *criteria for evidence of harm* should be flexible and open to debate. These criteria determine how risk is represented. They consist of for instance the time period over which a technology is assessed, the models that underlie the assessment of a risk, the kind of effects on which the technology is assessed, etc. This claim, which will be dealt with extensively in the next chapter, does not imply that any input from anybody has to be accepted into the process of risk assessment, which brings us to the next point.

#### 1.3.2. Quality of arguments

For both the first two stages of risk assessment, which are mainly meant to produce knowledge on a specific technological risk, as for the third stages, which

is mainly a moral evaluation of the balance between the burdens and the benefits associated with a technological development, the input provided by the various participants has to live up to certain criteria used to determine its validity.

Individual perspectives in decision procedures concerning the acceptability of technological risks will have consequences for other individuals. Should an individual demand that SUVs are prohibited, and should her demand be granted out of respect for her autonomy, this would seriously impact other people's autonomy. It is reasonable to impose certain quality requirements on claims concerning the acceptability of a technological risk. If an individual for instance claims that driving a SUV is acceptable because it increases safety, this claim needs to be substantiated. Whether such a claim is acceptable, depends on the scientific credibility and the moral acceptability of the claim. In this case, the claim, it appears, may be dismissed on both these grounds.

Firstly, most drivers may feel safe inside a SUV, but for pedestrians in an accident that involves a SUV the risk of a fatal outcome double. So possibly the safety of the driver of a SUV increases, but not that of other road-users. The moral acceptability of this claim is questionable as it only concerns one individual and neglects the interests of other individuals. Other participants in the debate should therefore not feel compelled to respect this claim.

Secondly, even the safety of the driver of a SUV is less than that for other cars. SUVs are known to topple over when they crash, instead of sliding forward as other cars do (see Kweon & Kockelman, 2003). This substantially increases the likelihood of serious injuries to the people inside. The perception of the safety of the driver is hence not compatible with scientifically produced knowledge on SUV's, and therefore should not be considered to hold a normative appeal to other participants in a debate.

Assessing claims put forward in debates on the acceptability of technological risks will impact on decision procedures and might make them more manageable because some claims can be dismissed beforehand. This makes the decision less complex than if all claims have to be considered, regardless of their scientific and moral tenability. However, disputes on the acceptability of technological risks are often characterized by a high degree of uncertainty. Which arguments are conclusive in such debates is rarely clear beyond doubt, and not all disputes will be resolved solely by assessing the arguments put forward. When it comes to increasing respect for autonomy within such debates, assessment of the arguments offers an important contribution.

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The current lack of criteria to assess arguments may have hampered the influence of laypeople on risk assessments. As said above, it has often been feared that laypeople lack the competences to provide such quality. However, to dismiss the input of laypeople categorically seems to be mistaken, as numerous authors have indicated. In many cases, the input of laypeople has contributed to the quality of the risk assessment (see Kluver *et al.*: 2000; Shrader-Frechette: 1991b; Kaplan: 2000; Hassanein: 2000; Wynne 1996a). To ensure the quality of such decisions it is desirable to assess the arguments instead of excluding an entire group of people from influencing the decision concerning the acceptability of a technological risk.

### 1.3.3. Burden of proof

The third issue that should be considered when designing decision procedures that respect autonomy in relation to technological risk is the asymmetry in access to resources needed to provide reliable technical data on which to argue a case. Not every individual (party) has access to the resources to provide the scientific reliability demanded of arguments. Funds, skills and equipment are usually not within the reach of most laypeople. Since the arguments put forward in decision procedures on technological risk have to be of a certain quality, the burden of providing that quality increases, compared to debates in which quality requirements are not so explicit. Actors who have access to the required resources have an advantage over actors who lack such resources.

If the representation of a risk is controlled by those with the resources to describe risks scientifically, often those with a vested interest, the perspectives of those without such resources might be marginalized. This would seriously limit their autonomy. Those without the resources to provide scientific evidence, should be allowed to influence the criteria for evidence of harm, but they can not be required to provide evidence of harm. Should specific scientific evidence be required to determine the acceptability of a risk, the party with the resources suited to this purpose should provide the evidence.

## 1.4. Substantiating respect for autonomy

### 1.4.1. Outline of this research

To achieve the above mentioned amendments in a way that respects autonomy requires the articulation of a concept of autonomy that is applicable to the conditions of our highly technological society. Traditional accounts of autonomy such as conceptualized by Kant, Mill and feminist authors all offer valuable starting points for such a concept, but they nevertheless also have some drawbacks. The concept of autonomy developed in this research is an effort to overcome those drawbacks.

The concept developed in this research is called 'narrative autonomy'. Aside from being specifically apt to deal with the kind of questions posed in this research, the aim is to acknowledge and incorporate explicitly the relation between the autonomous individual and her social environment: a relation the understanding of which is essential for dealing with issues involving autonomy in any area of life. This will be done by incorporating the notion of identity into our understanding of autonomy. An extensively developed account of this concept is provided in chapter 3.

Before chapter 3, I will discuss more extensively what is required of a decision procedure that respects autonomy in technological risk and hence what is required of a concept of autonomy in chapter 2. I will also discuss why the mechanism of IC is insufficient to deal with autonomy in technological practice. I will do this by discussing the differences between medical and technological practice. This will result in an agenda for respecting autonomy in technological practice and a set of requirements for a useful concept of autonomy. For instance, we need a concept of autonomy that allows us to distinguish between autonomous and non-autonomous judgments. To ensure that individuals are not burdened with appeals from other individuals that are insincere or unreflected, only those arguments that can be truly considered to have been made autonomously should elicit respect from other participants in decision procedures on technological risks. For instance, a concept of autonomy in which self-expression in any form is considered an act of autonomy, would become problematic in the context of technological risk. As said above, we need to be able to distinguish the quality of the arguments put forward to respect the autonomy of all participants instead of only one or some, participant(s).

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Chapters 4-6 consist of case-studies of three different areas of dispute in technological risks. Each of these cases is analyzed according to the concept of narrative autonomy presented in chapter 3. The trade-conflict about genetically modified crops between the United States and the European Union is described in chapter 4. This case-study illustrates why it is so important to make criteria for evidence of harm flexible and open to debate when it comes to respecting autonomy. Additionally it underscores the importance of assigning the burden of proof according to capacity. It further shows how a neo-liberalist version of autonomy, which is rooted in Millian autonomy, leads to undesirable consequences in decision procedures on risk.

The debate on the safety of vaccination of children in the Netherlands is described in chapter 5. This debate illustrates why it is necessary to assess the quality of arguments for decisions that might have consequences for other people. This case furthermore shows why narrative autonomy allows for constraints that are more apt to decision procedures on technological risks than feminist or Kantian accounts of autonomy.

The debate on the risks associated with mobile phone technology in the Netherlands is described in chapter 6. This case integrates all the required amendments to existing decision procedures. As such it offers material to evaluate the proposed recommendations as based on the concept of narrative autonomy.

The findings of all three case-studies are drawn together in chapter 7. An evaluation of the concept of autonomy developed in this research with reference to the results from the case-studies is presented. This chapter also contains the conclusion of this research.

### 1.4.2. Method

The relation between the empirical and the theoretical part of this research is slightly different than commonly found in other research, as this is a distinctly normative dissertation. The aim is to describe how things *should be* and not how they *are*. The theoretical part of this thesis corresponds with the normative aspect, and as such, the process of theory formation is rather insensitive to how things are. However, the empirical input serves to refine the theory of autonomy so that it does justice to actual problems with autonomy met with in daily

technological practice and helps to produce recommendations for practice that are feasible.

The research presented here is an instance of empirical ethics, in the sense that it is based partly on empirical data. As such it should be considered *context-sensitive* ethics: ethics in which findings from social sciences are seriously regarded and an attempt is made to incorporate such findings while developing ethical principles and theories (see Musschenga: 2005, 23).

This approach contrasts with *contextualised* ethics, which “..starts from the opinions and conducts of those involved in a social practice and rejects importing alien, external principles into a context” (see Musschenga: 2005, 17). Contextualised ethics is often applied in the field of medical care.

In contextualised ethics the intuitions of the practitioners themselves are considered of paramount importance as the practitioners are the ones who have direct access to the specific circumstances of a practice. In support of this approach it has been argued that morality arises in practice, not in theory. The ethicist can only explicate and reflect on that morality, she cannot herself construct that morality (see Scheer, vd & Widdershoven: 2004).

Instead, context-sensitive ethics may also incorporate the opinions and conducts of those involved in a social practice, but will do this only in a highly critical manner. It is believed that a thorough ethical analysis of a situation requires the eye of a detached observer such as an ethicist (see Scheer, vd & Widdershoven: 2004). The people involved in the social practice are too much shaped and influenced by that practice to be able to reflect critically on it.

Both stances have some truth in them and the reasons behind them are acknowledged and taken into account in this research. However, this research will be explicitly characterized as context-sensitive ethics. Context-sensitive ethics is most suitable to this research since a principle that does not explicitly function at the foreground in technological practice, namely the value of respect for autonomy, will play a central role.

There is a long tradition of consideration for patient autonomy within medical practice. In engineering practice this concern for the autonomy of the individual is not so explicit. The value of respect for autonomy is not inherently embedded in technological practice. As such, the reflections of engineers and other relevant professionals on this issue will be less valuable in a less direct manner than if this was research on autonomy in medical practice.



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The judgments of the practitioners of technology will still carry substantive weight in this research, especially in those areas where I have no formal training myself, but also on issues with a moral character. These judgments will however not be taken at face value, which is how contextualised ethics proceeds. The judgments of the people 'on the floor' will be critically assessed before they are incorporated in the analysis of the issues at stake.

## 2 A comparison between medical and technological practice<sup>1</sup>

### 2.1. Introduction

As described in the previous chapter, technological risks and the value of respect for autonomy currently form a problematic relation. Individuals often have very few options when it comes to influencing decisions regarding technological developments and the accompanying risks in a way that accords with their own particular moral framework.

The problem of respect for autonomy in relation to risks has also been identified in medical practice, and to address this problem in this context, the procedure of Informed Consent (IC) was introduced.<sup>2</sup> With IC, patients, after having been informed by the physician about the risks and benefits associated with a proposed treatment, are explicitly asked to consent to the treatment before it is commenced. This procedure is also used when patients participate in experimental treatments for research purposes.

In light of the above, and to counter some of the ethical deficiencies related to the lack of autonomy in technological practice it has been proposed that IC-procedures should be introduced within this practice (see Martin & Schinzinger: 1983). The central question in this chapter is: Given the differences and similarities between technological and medical practice, how should autonomy be respect in technological practice? Is IC a suitable means to this goal or should we pursue a different strategy?

Technological practice here is understood to be all those activities that bring forth and maintain technological artefacts<sup>3</sup>. Medical practice is understood as activities performed within the boundaries of modern medical science, which

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<sup>1</sup> This is an extensively revised version of Asveld (2006).

<sup>2</sup> Historically, the introduction of the procedure of Informed Consent followed the Nuremberg trials at the end of the 2<sup>nd</sup> World War. These trials in part concerned the inhumane medical experimentation on human subjects by Nazi doctors. To prevent such horrors ever occurring again, principles such as Informed Consent for medical practice were formalized in the Nuremberg Codes.

<sup>3</sup> I understand artefacts to include products and technological processes and systems.

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center on the human body. The focus of technological practice is on the development, production and maintenance of artefacts intended to increase human welfare. Medical practice is concerned with developing artefacts and treatments that are intended to cure or bring relief to human beings and protect their health.

The distinction between the two forms of practice may not be so clear cut as presented here. Medical practice, for instance is commonly technological in character. In this respect, medical practice might be seen as a subfield of technological practice, with specific characteristics that warrant treatment of this field as separate in nature. The overlaps between the two fields do not invalidate the search for distinctive qualities. Granted that there are similarities, the interesting question remains: Where do they differ? More specifically: How do such differences relate to the process of accommodating individual autonomy in relation to establishing the acceptability of risks?

Usually, the acceptability of a specific risk is determined through the procedure of risk assessment. Risk assessment consists of three distinct stages: identification, estimation and management (see Shrader-Frechette: 1991, 5). First a risk is identified, secondly the risk is estimated and thirdly, a decision is made as to whether a risk is acceptable and if so, how the risk should be managed. I will discuss the salient differences between medical and technological practice with regard to the possibility of an individual influencing the decisions concerning acceptability of risk by considering these three stages. I will discuss the stage of identification and estimation in the same sub-section, because similar considerations are relevant for both these stages. I will refer to the outcome of the first two stages as risk- representation as a specific description of a risk is given.

It is argued here that to respect autonomy in relation to technological risks decision procedures should be amended relative to IC in three important respects. Firstly, with regard to the first two stages of risk assessment; they should be as equally open to input from laypeople as the last stage. In IC laypeople are supposed to contribute only to the evaluation of risk while respect for autonomy in technological practice requires that laypeople can also contribute to the representation of risk. Secondly, the third stage of risk assessment: the evaluation or management of risk, should include a discussion concerning the desirability of technological developments. Such issues are commonly not discussed in IC. Thirdly, in general, any arguments offered in

decision procedures on risk need to be assessed on quality. Only those judgments that live up to certain criteria can be considered autonomous judgments that deserve respect. In IC, the patient does not need to justify her decision to anyone else. In technological practice where most developments affect people collectively, the individual will need to justify her positions on the acceptability of risk, as her position might have consequences for others. Lastly, to integrate all these amendments, decision procedures in technological practice should take the format of public and political debates, while IC is a solitary exercise.

### **2.2. Identification & estimation of risk**

#### **2.2.1. Representation and underlying assumptions**

As said above, to respect an individual's autonomy in technological practice requires that the identification and estimation stages of risk assessment are open to input from laypeople. The way a risk is represented strongly depends on the assumptions underlying that representation. These assumptions spring from the world view of the risk assessor. The representation of a risk will have a substantial impact on the actual acceptance of that risk. Therefore, in respecting the autonomy of individuals, it is important that the risk under scrutiny is represented in a way that accords with the specific worldview of individuals. Additionally, there is a need to including laypeople's perspectives in the representation of risk as this will increase the epistemic quality of the representation.

Risk assessment begins with the identification of risk. This stage relates to the question: What developments should we be concerned about as possibly posing risks? Can we expect the potential side-effects of a new medicine to equal those of an existing medicine that has similar properties? Should we consider a new production method for known food products to be a reason to re-assess their safety? When designing a new artefact, should we include all forms of possible abuse of the artefact in an assessment of its safety?

Which developments we identify as risky and which not depends to a large degree on our social and (sub)cultural backgrounds (see Adams: 1995), or what we might term our worldview: our specific outlook on and how we comprehend of the world around us. I will illustrate this with a discussion on the safety of

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genetically modified maize which took place among the academic community at Berkeley University. In 2001 two researchers from Berkeley University, Ignacio Chapela and David Quist, published a paper in *Nature* on the contamination of Mexican maize varieties with genetically engineered varieties of maize. These findings were highly alarming since Mexico has tried to remain free of Genetically Modified Organisms (GMOs) to protect its score of traditional varieties from cross-pollination with genetically engineered varieties. Chapela's and Quist paper showed that this attempt had failed (see Platoni: 2002; Gerdes: 2002; Tonak: 2004).

The research was severely contested by several other scientists, including two graduate students from the same university. The debate concerned two related claims. Firstly, that Mexican maize had been contaminated, and secondly that gene constructs are unstable once they are inserted into their hosts. Unstable gene constructs may cause unwanted and unexpected changes to the genetic make up of an organism. Both of these claims were thought to be impossible by the opponents. The opponents were convinced that crops and their pollen could very easily be contained and controlled. They furthermore believed that artificially created gene constructs are not very different from naturally occurring gene constructs, implying that both would be equally stable. If artificial gene constructs are proven to be unstable, this would imply that they are different from natural gene constructs. Moreover, they should not be considered a reliable technology.

It turned out that the methodology Chapela and Quist used was somewhat flawed, as they later admitted themselves, although not entirely unreliable. Therefore, in an unusual move, *Nature* retracted support for the paper, but not the paper itself, because its major conclusions still appeared to be justified due to additional evidence not included in the original paper. Later research showed that the Mexican maize had indeed been contaminated, although not by pollen traveling hundreds of miles through the air, as was the previous explanation of the contamination, but because Mexican farmers had illegally planted engineered maize varieties. Additionally, other evidence has shown that the instability of gene constructs cannot be excluded, but that it also cannot be definitely confirmed.

In this case, both sides appear to have been guided very much by how they understood genetic engineering and the (alleged) associated risks, instead of tangible evidence. Chapela and Quist had condemned the genetically engineered

maize while lacking conclusive reliable evidence; their opponents followed a similar strategy when trying to repair the tarnished image of genetically engineered maize. The debate continued to rage, involving groups and individuals with strong views regarding the safety and desirability of genetically engineered crops in general, with groups like Greenpeace supporting Chapela and Quist and groups like the think-tank AgBioWorld, that advocates biotechnology, condemning Chapela and Quist's findings. A piquant detail is that the whole controversy raged against the background of a lucrative contract with the biotech-company Syngenta that had divided the Berkeley scientific community over its desirability, notoriously along the same dividing lines that separates the supporters and the opponents of the Chapela and Quist research.

This above illustrates how presuppositions can influence the identification of risks. In terms of John Adams' (see Adams: 1995) version of the cultural types first proposed by Douglas and Wildavsky (see Douglas and Wildavsky: 1982), each party in this debate can be recognized as a specific cultural type. Although these types are crude representations of a wide variety of social and cultural outlooks, they can be used to illustrate how such outlooks can influence how we comprehend risk. The parties supporting Chapela and Quist, including the researchers themselves, belong to the type termed 'egalitarian' (see Adams: 1995; Douglas and Wildavsky: 1982). The parties opposing Chapela and Quist can be said to belong to the type termed 'individualist'.

Egalitarians are characterized by a perception of nature as vulnerable. Any uncareful human action may disturb the natural balance to the point of destruction. This perception on nature is often accompanied by a strong sense of social justice, in which weaker parties, humans and/or other living creatures, need to be protected against stronger parties who might easily exploit them. This perception is often found among environmental activists and associated groups. Individualists to the contrary, view nature as 'benign' (see Adams: 1995, 88-91), which implies that any natural balance is conceived as sturdy enough to survive human disturbance. This view of nature is usually accompanied by a belief that human beings, and other living creatures, should, and can, take care of their own interests individually. This perception is associated with (neo-)liberal proponents of the capitalist system.

These cultural stereotypes can be applied to explain the differences in the Mexican Maize-controversy. Indeed, Greenpeace took the side of the 'egalitarian' Chapela and Quist, while a big agricultural company (Novartis) and their

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advocates (AgBioWorld) took a stance against them. They can be considered 'individualist'. Although these stereotypes will not always fit every controversy, they do illustrate how different worldviews can influence the identification of risk. The egalitarians feared that cross-pollination could occur across hundreds of miles, and they perceived gene-constructs to be unstable: an attitude that reflects a view of nature as vulnerable. The individualist in contrast thought this was very unlikely, holding a view that gene-constructs are stable: a view that perceives nature to be robust.

The next stage of risk assessment that is relevant to the representation of risk is the estimation of risk. This stage is likewise influenced by the specific world view of the risk assessor. This stage relates to the question: How severe do we assess the identified risk to be? The severity of a risk is usually conceptualized as 'chance times effect', i.e. the probability that a hazard occurs multiplied by the severity of the effect. The estimation of a risk depends on the assumptions that underlie the identification of the risk. How is a risk modeled? Which inferences from laboratory experiments are considered to be justifiable? How long is the elapse time envisioned between cause and effect? What kind of human behavior is thought to provoke dangerous situations in relation to the use of the artefact in question? What is the probability of relatively rare events? (see Fisschof *et al.*: 1981, 18; Jasanoff: 1991, 34; Silbergeld: 1991).

A typical form of risk representation usually begins with identifying the causal chain of events that may lead to a certain risk event and 'adds up' the probabilities of these events occurring. The identification of these events and especially the question where to limit the chain of events in time, however is not transparent. Should one consider the risks attached to hydrogen fuelled cars from the moment the car is actually driving, or should one also include the sustaining network of hydrogen pumps, hydrogen transportation and hydrogen storage as well? Additionally, should one also include the risks involved in replacing the old gasoline infrastructure or not? Again, the answers to such choices will to some extent depend on the personal and institutional background of the researcher, and in some cases, as Krinsky (2003) has shown for pharmaceutical research, also on the financial ties of the researcher.

There are many choices present in methods of risk-representation, comprising both the stage of identification and that of estimation, that leave room for individual interpretation. In relation to nanotechnology for instance, the question whether nanoparticles can penetrate human skin is answered

differently by different scientists. This disagreement can be explained by the different methods used to test for the penetration of nanoparticles. Whether the research is based on living tissue or non-living tissue might for instance make a difference, or what preparation method is used, because the nano-particles might be washed out in the preparation phase (see Nett: 2004, 18).

Although risk representation has subjective elements, it can still be considered a relatively robust method for assessing risk. Robust in this context implies that knowledge is generated in a systematic, structured way, and can be criticized and contested as such by other parties (see Shrader-Frechette: 1991b). This makes it different from risk-perception, which is understood here as representation of risk which arises outside methodological procedures such as a thorough risk assessment. Risk-perception includes most associations laypeople have about risks. Risk-perception does not need to be disqualified as unrealistic; it is just not systematized and scrutinized the way risk-representations are. A risk perception may be scientifically tenable, even though it has not been scientifically tested. A risk-perception is in such a case compatible with scientific knowledge relevant to understanding that specific risk.

Both risk-representation and risk perception are characterized by subjective elements. However, risk representations arise out of methodological procedures that have proved to be useful in producing knowledge about risks. These methodological procedures enable relevant criticism from others besides the researcher, because the choices made and the steps taken should be accessible to other people. Reasonable risk perceptions from other individuals besides the original researcher can be incorporated in risk assessments, thereby enabling the representation of risk to reflect several perspectives, instead of only one, or alternatively to illuminate on what aspects a risk assessment can be said to be subjective.<sup>4</sup>

The subjectiveness of risk assessment is, in this research, not considered to undermine the usefulness of risk assessments (cf Shrader-Frechette: 1991, ch. 3). Risk assessments are regarded as relatively useful instruments for identifying and estimating a risk. Even if risk assessments do not produce conclusive knowledge on a specific risk, they do offer useful representations of risk, which can help us to illustrate arguments in disputes about risks.

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<sup>4</sup> What 'reasonable' amounts to in relation to risk assessment will be explained in the remainder of this dissertation.



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Assumptions underlying the representation of risk give rise to specific *criteria for evidence of harm*. These criteria determine the range of likely harmful effects connected to a specific artefact and hence the design of the experiments conducted to establish the existence of harm. These criteria influence the parameters for safety-research performed on a specific artefact. Some effects will be excluded by these criteria from association with a specific artefact because they do not accord with the assumptions that model the risk representation. One such criterion might for instance be the time lapse between cause and effect. The criterion may imply that if no effect is measured in the envisioned time-lapse that the artefact is considered safe, for that specific effect at least. As we will see later, in debates on the acceptability of risk, these criteria are very often a matter of dispute, both for laypeople and for experts.

The way a risk is represented will have a substantial impact on the actual acceptance of that risk. Therefore, in respecting the autonomy of individuals, it is important that a risk is represented in a way that accords with the specific worldview of individuals. Hence, it is important that the underlying criteria for evidence of harm are opened to discussion. If we acknowledge that reasonable disagreement on risk representations is possible, and if there is indeed such disagreement about risk representation among the experts, the testimony of one expert with regard to a risk can never suffice. The representation put forward by one particular expert may not be the representation that best reflects the interests and worldviews of the other participants' in a debate on the acceptability of a risk. Additionally, it should be common practice for laypeople to be able to bring forward alternative risk perceptions, as long as these are within reasonable limits.

Apart from supporting increased respect for individual autonomy, this approach has another benefit. Laypeople can offer valuable additions to scientific knowledge on risk (see Kleinman: 2000; Shrader-Frechette: 1991b, 2002; Wynne: 1996a). They often know their own environment very well and can easily detect changes. They may have a perspective on technology that helps researchers understand a risk in a new light. Laypeople will know how a technology is eventually applied and how it interacts with other artefacts. As such, their input may prove indispensable to the epistemic quality of risk assessment.

### 2.2.2. Differences in risk representation in each practice

In medical and technological practice different approaches exist with regard to the possibilities of laypeople to influence representations of risk. These differences might be explained by the general differences between these two practices in producing representations of risk. I will discuss some characteristics of both practices that may imply that the assumptions relating to specific worldviews cause less uncertainty about risks in medical practice than in technological practice. This has consequences for the inclusion of laypeople in the first two stages of risk assessment.

In technological practice, the realization that the representation of a risk should, to some extent, be opened up for the input of laypeople, has impacted the efforts of experts and policymakers to include laypeople in decisions on the acceptability of risks. In many European countries, laypeople are being increasingly invited to participate in decisions regarding the acceptability of technology, in the form of Participatory Technology Assessments (PTA). These assessments resemble the procedure of obtaining informed consent before a medical procedure is carried out on an individual in that the participants are first informed about the technological development at stake and its accompanying risks, and then get an opportunity to form an opinion about this technology.

In medical practice however, the procedure of IC usually involves only one expert and a limited role for the layperson with respect to the representation of risks. The procedure of IC is usually understood as the physician *disclosing* information on a specific (experimental) treatment to a patient, who can after considering this information, either consent to the treatment or refuse it. The term disclosing implies one-way provision of information from the physician to the patient. This does not allow for a substantive contribution from the layperson regarding the representation of risk.

The representation of risk in medical practice is assumed to involve both diagnosis as well as treatment. Whether a patient accepts the risks associated with a specific treatment is related to the identification of the medical condition for which treatment is required. Additionally, the diagnosis might be something a patient rejects, because she feels it is inadequate. Moreover, an incorrect diagnosis also represents a risk. If the diagnosis is incorrect, the required treatment will encompass another set of risks. However, it is uncommon for a patient to be offered a variety of possible diagnoses during the process of informed consent, unless the patient explicitly requests a second opinion.

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The basic theory behind the design of informed consent does not assume that patients might need various representation of a given risk in order to make an autonomous decision about that risk (see Faden & Beauchamp: 1986).<sup>5</sup> In medical practice, a patient may be confronted with various representations of risks associated with a specific treatment or with various diagnoses by several physicians; this is however not considered to be an elementary part of the procedure of informed consent; patients are supposed to receive coherent information (see Legemaate: 2001, 12). In contrast, in technological decision procedures such as PTA, representation of a given risk from various perspectives is usually an essential element of PTA-procedures.

Several qualities of medical practice compared to technological practice, to be discussed below, may explain this difference. There are reasons to suppose that the assumptions relating to specific worldviews cause less room for divergence with regard to the representation of risks in medical practice than in technological practice. The existence of these reasons does not necessarily lead to the conclusion that knowledge of risk in medical practice does not suffer from uncertainty, or even that it suffers less from uncertainty. These reasons merely imply that the way knowledge on risk is produced in medical practice leads to a less wide-ranging kind of disagreement among practitioners than in technological practice. Therefore, a different procedure is applicable when it comes to accommodating individual autonomy in technological practice, than that found in medical practice.

The difference between medical and technological practice boils down to a difference on a continuum, rather than a difference in kind. The above remarks about the divergence in representations of risk apply to risk assessment in both practices. Within this general outline of risk assessment however, reasons exist to expect variance in the degree of divergence that characterizes the different risk

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<sup>5</sup> Three different standards exist to structure the communicative process between physician and patient. These standards are known as the professional standard, the subjective standard and the reasonable person standard. The first two standards are rather general guidelines directed at the risk-communication of the physician that apply irrespective of the specific interests of the patient. The third approach is intended to provoke a dialogue between physician and patient. This dialogue functions as an instrument to uncover what information should be disclosed. Although the patient is allowed more influence on the process of information provision according to the latter standard, the basic structure remains one of the expert providing information with the patient acting in a more or less passive manner.

assessments and this variance may warrant different communication procedures between expert and laypeople with different roles for each group for each practice.

The reasons to assume that different communication procedures are required for each type of practice are threefold: one, in medical practice new products are extensively tested in controlled environments, additionally, two, the application of a new product is very narrowly defined, finally, three, medical practice can be qualified as a socially more closed system than technological practice. I will discuss these three qualities of medical practice below.

### **2.2.2.1. □ Controlled environments**

With regard to the first point: in medical practice new products are usually extensively tested in controlled environments before they are tested using human subjects. The fact that new drugs are tested in controlled environments reduces the variation in the assumptions made regarding the assessment of their safety. In a clinical research environment, there is more consensus on what should be considered a risk, and hence what should be tested.

In contrast, the release of most technological products in society is less controlled than that of medical products. Most medical products may only be applied by qualified professionals using prescribed procedures, other products can only be used by people who have obtained prescriptions, based on need, from qualified professionals. This makes it easier to identify which possible factors might contribute to a risk event.

It can be objected that many technological artefacts are also solely applied by qualified professionals, such as building equipment, and that many technological artefacts should only be used according to specific prescriptions. However, the widely varying environments in which most technologies are used, makes it less probably that prescribed procedures will be invariably followed. The clinical setting of a hospital makes this much more likely. Additionally, whether artefacts are used properly in technological practice by both qualified professionals and laypeople is usually not controlled as extensively as in hospitals, or when medication is taken in the private sphere, but still under the supervision of a physician.

This is not to say that medical practice is necessarily a lot safer than technological practice. However, the kind of risks in medical practice can be said to be easier to describe. This implies that when in an IC procedure a patient or a

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research subject decides on the acceptability of a risk attached to a certain treatment or experiment, the knowledge of the risks involved can be presented in a more homogenous manner than is the case for technological risks. This is true for treatment as much as it is for medical experiments.

### 2.2.2.2. Narrow definition of risk

Secondly, many of the uncertainties in technological risk representations arise out of differences in assumptions present in the models applied to determine the safety of an artefact. These assumptions may involve the way a technological artifact is used and under which circumstances, what kinds of events might cause it to malfunction, how it will affect its environment. Such assumptions are very likely to diverge considerably among risk-assessors, since they cover a whole range of environmental, human and technological qualities and reactions that are hard to predict, either because of a lack of knowledge or due to the sheer complexity of the situation.

In contrast, the medical context appears to be more predictable. Knowledge of medical risks basically concerns the interactions between a human body and a treatment, and such knowledge is characterized by an interaction of a more confined array of factors than technological risk assessment. Technological risk assessment includes adverse health effects, but also such risks as pollution, failure of artefacts, natural disasters and detrimental human behavior. Technological risk assessment therefore has to process input from many different sources, whereas medical risk assessment usually deals with one discipline.

It may be objected that within medical science many different perspectives on the human body also exists, for instance between between different specializations. An oncologist may have a totally different view of the causes of specific disability than a cardiologist. These different views can give rise to totally different risk assessments for specific treatments and divergent perspectives on viable alternatives. Even though such differences will very likely occur, quite possibly even within one area of specialization, the claim here is that compared to technological practice, these differences will be smaller.

Additionally, knowledge of medical risk is produced within the medical laboratories and institutions where the complexity of interacting factors can relatively easy be modeled and reduced following standardized procedures. Therefore, the assumptions that underlie the descriptions of risks can be

expected to vary in medicine to a lesser extent than the risk assumptions made in the technological practice. It may very well be that these assumptions still differ enough to warrant a different communication protocol during informed consent in a medical situation, for instance by presenting conflicting views on a treatment and its associated risks. The point made here is mainly that compared to medical practice, the underlying assumptions in technological practice can be expected to be more varied and that therefore, as a minimum, in technological practice, a different procedure for accommodating autonomy is required.

The point is the nature of our knowledge of risk. Knowledge production is a social process. The social institutions and relations that underlie each of the practices are fundamental to understanding the generation of knowledge of risk. The social practice of medicine is more confined than that of technological practice; it therefore leads to more narrowly defined risks. This does not necessarily relate to what the risks amount to precisely, it concerns primarily the way the risks are interpreted and described. It may be that the interaction between the human body and a medical treatment is epistemically equally obscure as the interaction between an artefact and the possible environments in which it is used. However, the social context in which knowledge about the human body and medical treatment is generated, leaves much less room for variations in underlying assumptions than the social context in which knowledge on risk associated with technological artefacts is generated.

### **2.2.2.3. □ Closedness of the medical system**

This brings us to the third point about the closed nature of the medical system. Medicine is a closed system to a larger degree than technology: conventional medical institutions are very recognizable and one is either an insider or an outsider. This becomes clear for instance in the fact that not everyone can take part in medical activities whereas technological development can be undertaken by anyone who is willing to get involved. Medicine is a profession with an internal judicial system, which implies that doctors can be expelled from their professional group if they are convicted of malpractice. In the United States, such a system also exists for engineers but only for engineers not working in industry. The European Union does not have such a system. Engineers do not require a special license in the EU to demonstrate their trustworthiness to third parties.

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Additionally, a strong boundary exists between what are considered to be legitimate means and practices and what are not. Alternative medicine is a clearly distinguished medical system. Patients who turn to these practitioners can do so at their own risk and they are often considered to be less rational for taking such a course.<sup>6</sup>

In technological practice quality cannot so easily be judged solely by the identity of the institutions that disseminate technological products. A wide variety of actors produces technological artefacts, for example companies, universities, inventors and research institutes. There is no formal system to distinguish between the actors, except for universities as they are part of a scientific assessment system. The ISO 9000-standards are an instrument to assess quality in technological practice, these serve as benchmarks for reliability and safety. However, compliance to the ISO-9000 standards is mostly voluntary.

Medical and technological practices share a need to distinguish between reliable and unreliable *knowledge* and use the distinctive qualities of institutions to assess such knowledge. In the Netherlands for instance, the Health Council of the Netherlands has as its task the requirement to monitor available scientific knowledge on specific subjects and to advise the government on the severity of the (alleged) risks in question, both technological and medical risks.

However, when it comes to actual practice, the boundaries between conventional, scientifically validated practice and scientifically not validated practice are less clear cut in technological practice. There is no such thing as pseudo-technology. There is better or worse technology for which distinction marks exist, but not in such a robust, general fashion as in medical practice.

The closedness of the medical system is further strengthened by the professional loyalty that exists among physicians. Loyalty to one's colleagues and teachers forms the first part of the Hippocratic oath. This loyalty makes public discussions of controversies and the reporting of poor practice less likely than in technological practice, where such loyalties may exist, but only implicitly. This implies that patients, who are not part of the system of expertise, will not be

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<sup>6</sup> Lately the lines between 'alternative' medicine and conventional medicine appear to have become increasingly porous, as more and more professional medical associations welcome alternative practitioners into their fold due to the mounting popularity of alternative medicine, hence not necessarily because of the belief that it is a viable alternative (Borst, 2006).

confronted with the conflicts over the existence of a specific risk. Such conflicts are likely to remain within the confines of the profession.

The closedness of the medical system is related to the relative autonomy of the medical profession. Medical professionals exercise and define the aims of their practice: namely promoting human health. It is a goal that is defined internally to practice. They do not need to rely on external sources of knowledge the way engineers do. The professional groups that practice the art and science of medicine also provide the knowledge used to define human health. The 'self-sufficiency' of medical practice explains why it is more of a closed social system of knowledge production than technological practice.

In technological practice engineers aim to serve goals that they do not define by themselves; instead the goals are defined in communication with clients and regulatory institutions that serve to protect the interest of the public at large. Furthermore, engineers rely strongly on other scientific fields when defining the content of such aims as safety, environmental friendliness and economic feasibility (see Airaksinen: 1994). Conflicts about such aims often take place among a variety of actors, such as governmental bodies and organized groups of concerned individuals (see cases in chapter 5, 6, 7). Such discussions are not limited to engineers or technical researchers.

The exclusionary character of medical practice makes it easier to control common assumptions about the workings of the human body and its relation to the environment within the medical-scientific community. Digression from these common assumptions is less plausible than in technological practice where there is less unity in approach and less control on the production and application of products. Anyone engaged in conventional medical practice has to a substantial degree accepted the premises about human health on which the practice is founded. This is true for practitioners as much as it is for patients.

However, disagreement about the representation of risks among medical practitioners and researchers is still possible. The qualities described above might give rise to less disagreement about risk than in technological practice, divergence in the perception of relevant concepts such as human behavior, the human body, influence of the environment etc., can still be substantial even within medical practice, possibly due to the variety in sub-disciplines. Patients may even be confronted with such different perspectives during their treatment, but usually not during the ICprocedure (see Schermer: 2001, 80). This



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uncertainty regarding knowledge of risk in medical practice might eventually be cause for a re-evaluation of the procedure of IC.

A salient aspect of medical practice in relation to informed consent is that once people are asked to give their consent, they have already crossed a certain threshold. They have already accepted the premises on which medicine is founded, otherwise they would not go to a conventional physician or they would not participate in a conventional research project. Informed consent in medical practice is mainly a safeguard against abuse; it does not offer a forum to discuss more fundamental issues such as the appropriateness of the method used or the reliability of the model of the human body. Therefore, when the patient or the research subject evaluates a specific risk, the representation of that risk is generally not thought to be of much concern.

Discussion on the representation of risk do sometimes occur between patients and physicians when patients organize themselves in patients groups and try to influence medical research and sometimes even the definition of the relevant illness. Such groups might be thought to accommodate the autonomy of individual patients better than the procedure of informed consent since it allows patients more influence. Additionally, patients may request a 'second opinion' when they doubt the judgment of their own physician, which also lends room for divergence in the representation of risk.

Recent trends in the emancipation of patients and the increased influence of insurance companies (in at least the Netherlands) on medical practice has undermined the closed nature of medical IC. Developments in this area might lead to a redesign of the traditional modal of informed consent, as it becomes clear that the testimony of a single physician might not accord with representations of risk by other parties, such as patient groups or insurance companies.

For now, the reason why informed consent is still applied in its original design might partly be explained by the three qualities mentioned above; a clinical test environment, strict controlled prescriptions for the application of products and closed nature of the practice. These may be the reasons that patients are in the procedure of IC informed solely by one expert: their own physician and that there is relatively little room for laypeople to influence representations of risk. The divergence in the representation of risk is more widely varied and less strictly controlled by professional practitioners in

technological practice than in medical practice and this leads to an increased receptiveness to alternative risk perceptions brought forward by laypeople.

### 2.3. Risk-management

#### 2.3.1. Evaluating risks

The third stage of risk assessment: risk-management, relates to the question: Given the representation of the risk at hand, what course of action should be taken? Should we aim at increasing the number of nuclear installations within our national borders? Should we allow wide-spread production of genetically modified crops? Or for medical practice: Should I accept the risks associated with this treatment considering the benefits it presents? This stage of risk assessment explicitly involves moral considerations. In both medical and technological practice, the inclusion of laypeople in this stage is considered paramount for respecting the autonomy of the individual (see Faden & Beauchamp: 1986; Kluver *et al.*: 2000). Whereas for the first two stages, the contributions of experts are generally thought to be more authoritative than those of laypeople, in the last stage this is explicitly not the case.

With regard to this third stage of risk assessment one amendment is required for technological practice as compared to medical practice to respect autonomy. Namely that decision procedures should explicitly include a discussion of the desirability of technological developments. The reason is that the aim of medical practice is less contested than the very broadly defined aims of technological practice. As a result the aims of technological practice do not legitimize the means, whereas this is more often the case for medical practice. This difference has consequences for accommodating individual autonomy in each practice.

#### 2.3.2. Comparison of the aims of each practice

Medical developments will in general elicit less debate on fundamental issues than technological developments. Medical practitioners are commonly involved in a practice the main goal of which is generally unquestioned and the benefits of medical practice are embraced by most people. As Harris & Woods (2001) put it: "We all benefit from living in a society, and, indeed, in a world in which medical research is carried out and which uses the benefits of past research."

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Although most people embrace the fruits of medical practice, dissenting voices can still be heard, such as the concerns voiced by Ivan Illich (1976), who questions the alleged achievements of new drugs and research. He points out that many improvements in our health may not be due to better medicine at all, but to better hygiene and food. Moreover, he states, instead of curing people, physicians basically make people (more) ill. Other critical attitudes can be found among supporters of alternative medicine, who claim that conventional medicine has too narrow a view on the concept of health.

Whether these worries are valid or not, they represent a minority perspective. In Western society in general, there is a strong faith in the benefits of medical practices. This strong faith is reflected in what Callahan (2003) describes as the 'research imperative' in the medical context. This imperative refers to the willingness of several actors: industry, government and patient organisations alike, to invest large sums of money in medical research without questioning the effectiveness of such research.

This unquestioning faith appears to be much less widely embraced with regard to technological practice. As an illustration: genetic modification as a means to achieve health, i.e. genetic modification of micro-organisms, has remained outside the fierce discussion centering on genetic modification, implying that comparable technologies are assessed differently in different contexts. If it is true that the aims of medicine legitimizes its means to a larger degree than the aim of technological practice, this will affect how the procedure of informed consent should be applied in the technological context. People will generally have more and stronger concerns about technology in general than about medical applications. Since respect for autonomy is the main objective of the procedure of IC, it is necessary to find ways to take these stronger concerns of people, with regard to technology, into account. Such concerns impact considerably on the acceptability of risks associated with a specific technological development. Only if they are taken into account, will people really have the opportunity to pursue their claim concerning the acceptability of a particular technological risk.

Several reasons exist to assume that technological practice and accompanying developments are less easily accepted than those of medical practice and their accompanying developments. The first has to do with multiplicity in aims, the second with perceptions of naturalness, the third with perceptions of immediacy

and proximity, the fourth with the division of burdens and the fifth with the perceived motives of practitioners.

First, much of the resistance against technological development can be explained by reference to disagreements about its aims. There is usually more discussion about the purpose of technological development than about the purpose of medical applications. Technology, in general, can be applied to a wide variety of goals, which might not always seem as pressing as the goal of combating disease. Medicine is more or less a one-aim practice as opposed to the multiple-aims practice of technology.

In the resistance to Third Generation mobile phone antenna for instance (UMTS technology), a technology that offers extended use for mobile phones, including watching videos on one's telephone screen, the opponents of UMTS (3G) antenna gave as one of their motivations a lack of need for such a product: "(...) because these UMTS antenna do not serve any other purpose but luxury: the GSM antenna are more than sufficient for messages telephones; the new antenna are nothing but games antenna for addicted consumers."<sup>7</sup> The intended benefits of this technological development were clearly not recognized as such by these opponents.

Although people might agree that technology spurs progress and that progress is generally thought to be a good thing, the exact implications of what progress is and what is good about it still leave much room for interpretation. Such different interpretations may clash. Does progress entail more functions on mobile phones or does it entail less telecommunication? Does progress entail more mobility for more people, or does it entail a healthier environment?<sup>8</sup> The aim of a particular technological development is often not generally embraced.

It could be stated that it is not the aim of a new technological development that is subject to extensive debate, but rather the means available for achieving the goal of the technological 'progress'. So people might agree that alleviation of world hunger is a necessary element of progress, the main disagreement lies in the question as to whether genetically modified food is an appropriate way to achieve this. However, even if the appropriateness of means is a main cause of disagreement, the disagreement can still be expected to be less intense when the aim of the practice is unambiguously defined. 'Health', in this respect, is more

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<sup>7</sup> Text on pamphlet calling for public action against UMTS antenna, [www.stopumts.nl](http://www.stopumts.nl),

<sup>8</sup> Of course, some technologies may be able to combine different interpretations of progress, such as an environmentally friendly car, but often, such aspirations are mutually exclusive.

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straightforward than ‘progress’ and can hence be expected to raise less discussion than the more encompassing aim of technological development.

Secondly, the aim of medical practice, i.e. to cure, is intuitively more appealing than those of technological progress. What curing actually implies is a contentious issue. However, on a general level, a rather straightforward definition can be formulated. I will stick to the concept of cure as reflected in Norman Daniels (1985, 28) definition of health: “health is the absence of disease, and diseases (I include deformities and disabilities that result from trauma) are deviations from the natural functional organization of a typical member of a species.” This definition implies that to cure is to restore the natural functional organization of a typical member of a species.

What is important here is the normative connotation cure holds for most people. The aim of medical practice to restore a natural function, as given in the definition above, is easier to accept than the pervasive alterations that are brought about by technological developments, which appear to lead to deviations from a natural state rather than restoring something to a natural state. Like cure, naturalness is a contentious and often culturally biased notion, but nonetheless it is very appealing to those of us in developed societies. It carries with it a reference to a desirable, pure state of being, which is threatened by any kind of modern economical, political or technological progress.

An exception to this restoring function of medicine may be the practice of psychiatry where to strive for ‘restoring natural functions’ is less recognizable. It is also in this field that aim and methods used may spark more controversy than other branches of medical practice. While acknowledging this as a problematic instance, I regard psychiatry as atypical because the concept of cure and natural functional organization are highly contentious in this medical field. The case of psychiatry does support my thesis that viewing a practice as restoring a natural situation contributes to its acceptability, as a concept of naturalness seems more unattainable in the area of mental illnesses than in other fields of medical practice.

Thirdly, illness brings about a direct, pressing need, the alleviation of which often becomes a prime objective which supercedes other, more broad-ranging and abstract considerations. The perceived direct need for taking certain risks is stronger in medical practice than in technological practice.

If people are ill, or someone of their loved ones is ill, the prospect of cure may lead them to subject themselves or their loved ones to a system of expert

knowledge without questioning the system too much. As Schermer (2001) describes the situation in hospitals: “For patients, there was often not much real choice; a course of action was proposed or prescribed to them that they could either accept or refuse” (p.80). This situation appears to be regarded as unproblematic by most patients. “(...) for many patients, medical decision-making was not something they were very concerned about or wanted to take part in” (p. 85). People apparently depend heavily on physicians when they are ill and lack the strength or resources to question them.<sup>9</sup>

This observation is confirmed by the willingness of people to contribute to medical research that will eventually benefit themselves or others. In the case of biobanks for instance, people who were interviewed about their motivations to donate blood samples often stated they want to help others and the next generation, including their own children. People who did not donate blood samples, because they thought biobanks might pose a threat to privacy, felt guilty because of this (see Haims & Wong-Barr: 2004).

This willingness to contribute to expert health systems, the recognition of this in some cases as a moral obligation, might be explained by the fact that many people have some experience with disease. Most of us have suffered or know someone who has suffered from a disease. The desirability of a healthy life is generally beyond doubt, especially when the negative effects of disease have been witnessed first-hand.

If we consider the costs and benefits associated with medical applications compared with those of purely technological applications in terms of money spent to achieve a state of well-being for as many people as possible, then technical applications might very well achieve just as much as medical applications. However, the benefits of medical applications may generally be deemed higher, even if their net result would equal that of technological applications, because they are always bestowed on a specific individual, who is in immediate need of care, whereas the benefits of technological applications are more widely spread over a larger group of anonymous individuals, whose needs are perceived to be less pressing than those of a sick friend or relative.

Fourthly, aside from the strong appreciation of the benefits of the medical practice, the burdens of technology appear to be much more directly visible. Medicine is often confined to the boundaries of a given hospital and sometimes

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<sup>9</sup> This may be different for people who are ill for a long time, and who are not too debilitated. These are however the rarer cases.

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to the boundaries of a patients' home or an ambulance racing through the streets. Technology in contrast is commonly very visible in society, which renders the burdens of such technology much more directly visible.

Not all specific kinds of technologies are always visible. Nanotechnology and biotechnology for instance are not easily perceptible for the layperson. However, the point is that people may be better able to witness the negative effects of technology *in general* because they daily experience technology than they are able to judge the negative effects of medicine *in general* as they usually encounter this practice only in very specific instances, under circumstances, moreover, in which a direct need for medicine is felt.

Paying for your health insurance is usually less of a direct physical burden than having a chemical factory built near your house. In both cases, the individual does not benefit directly from the burdens that are imposed on her, only indirectly. However, the burdens may be evaluated quite differently as they have quite different characteristics. The first is a financial burden that may not always be easy to carry, but is not immediately life-threatening, such as the second burden. These qualities of medical versus technological burdens may explain the greater willingness to accept medical burdens compared to technological burdens.

Additionally it can be stated that the health insurance burden is at least shared throughout society, whereas the burden of the chemical installation is directed at one specific geographical area. It is much more difficult to accept this burden, when the benefits are not directly visible, than it is with the burdens of paying for medical practice. The general observation is that the benefits of medical practice are usually aimed at specific individuals while the burdens of paying for it are distributed over society. In contrast, in technological practice, the benefits are often accessible to society at large, whereas the burdens of the technology are imposed on a limited group of people.

Put differently, there will generally be less agreement on the necessity for a given technological development than there is for the necessity of a medical development or treatment, as the benefits are easily discernible for medical practice and always pressing, whereas for technological practice, the burdens are more easily discernible than for medical practice.

Fifthly, most healthcare practices and medical research are usually associated with hospitals and governments, and not with companies, with the exception of

pharmaceutical companies.<sup>10</sup> Several people stated in relation to biobanks that they would be less willing to contribute if they were asked by a company to donate blood for DNA typing (see Busby: 2004, 50). An absence of commercial interests generally contributes to the trust people put in expert health systems. To perceive the interests of the other party as compatible with your own increases the trust one places in the other party (see Baier: 1984). This is easier if there is lack of commercial interest. The development of technological artefacts often involves commercial interests.

In conclusion it can be stated that medical risks are usually thought to be more acceptable since they are typically considered to be legitimatised by the aims of medical practice for the various reasons mentioned above.<sup>11</sup> The IC procedure in the medical context therefore serves mainly to protect the patient from deception and coercion (see O'Neill: 2002, 97) and is not directed at a discussion on the aims of the proposed treatment or experiment.

For the reasons mentioned above, it can be expected that people are, in general, more concerned about the desirability of technological developments than about the desirability of medical developments. The fact that such choices are more often of importance to them, justifies their inclusion in the procedure used in the field of technology to accommodate individual autonomy. To exclude such issues from the procedure of informed consent will undermine individual autonomy, as individuals will be denied the opportunity to make and enact choices according to their own moral framework. If it can be expected that such choices will elicit little discussion and little concern, the conclusion can be drawn that the choices as made by the experts alone will overall coincide with the choices laypeople would deem most desirable. As it is, however, laypeople appear to have strong concerns about the (alleged) necessity of technological developments.

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<sup>10</sup> This perception might shift due to the increasing influence of pharmaceutical companies on scientific medical research (see Krinsky: 2003)

<sup>11</sup> However, it would be wrong to state that medicine has not experienced some of the distrust towards its institutions that has characterized the scientific and technological practice. The aim of medicine, to cure, does not always legitimize its means or its methods to everyone, as is shown by the growing number of people who turn to alternative health practitioners and the increased distrust of pharmaceutical companies. Such debates are however usually not conducted during the process of informed consent, though possibly they should be.



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Hospitalized individuals will usually have little desire to question fundamental issues underlying general developments in medical science. It can be expected that in medical practice such fundamental issues will usually not be discussed during the procedure of informed consent (see O'Neill: 2002, 38). Moreover, in general, people will have fewer reasons to question the necessity of medical developments since for most people the aims of medical practice seem to justify most of the risks associated with this practice.

However, this is not to say that the aim of medical practice justifies all means. Stem cell research for instance raises many concerns. I think that this debate is atypical for medical practice: it opens up concepts related to life and health in ways unprecedented by any other medical development. Some applications of stem cell technology intrude on natural functions, such as the development of an embryo, and go on to extend the functions of developed human beings beyond their usual natural capacities. In this sense, stem cell applications resemble technological developments more than conventional medical developments.

### 2.4. Exchange of arguments

#### 2.4.1. Justification of arguments

We have established that accommodating individual autonomy in technological practice requires that laypeople can influence criteria for evidence of harm and the aims of a technological development. To complicate matters even further, it is also necessary to take into account the perspectives of a variety of actors, instead of only one, because technological developments typically affect a variety of individuals.<sup>12</sup> This implies that participants in decision procedures will have to justify their arguments.

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<sup>12</sup> Although in medical practice decisions on the acceptability of a treatment are assumed to be made by one individual, this is actually often not the case. Often decisions are made by a group of people surrounding the individual. However, the individual patient remains to be considered the ultimate authority. Furthermore, the discussion as invoked by patient organisations usually have an impact on groups of people, all the more since they target issues such as research strategies, which includes spending public funds. Possibly these discussions should be conducted in public fora more than is happening now.

## A comparison between medical and technological practice

The *burden of proof* in providing reliable information does not rest exclusively with the expert in technological practice. In medical practice, all information material to decisions made during IC is related by the expert. The patient is not required to put forward any arguments to support her decision that can be assessed as reliable by others. There is no need for her to justify her decisions to anyone but herself. In contrast, since the position of the individual on a technological risk may have consequences for other people, a certain quality may be demanded of the arguments in support of that position. Only those arguments that can be recognized as autonomously made arguments carry a moral weight for other people.

Which criteria determine whether arguments can be considered autonomously made arguments depends on the concept of autonomy employed. As Onora O'Neill has argued the minimalist interpretation of autonomy that underlies IC is insufficient to deal with complex issues involving consequences on a collective scale such as environmental degradation and public health policies (see O'Neill: 2002, ch.2). IC requires a patient solely to make a decision, there is no assessment whether that decision is indeed an autonomous decision. O'Neill proposes instead to introduce the notion of principled autonomy, which is a form of Kantian autonomy. This concept of autonomy demands that autonomously made judgments meet certain constraints as will be discussed more extensively in the following chapter.

The next chapter is devoted to the explication of another concept of autonomy, narrative autonomy, which is assumed to be suited to the intricacies of decisions on the acceptability of technological risk. In that chapter I will also explain why I think this account of autonomy fares better than other accounts of autonomy in the context of technological risk. Any concept of autonomy that is useful in the context of technological practice will have to offer a platform for diversity, in order to incorporate the divergent representations and perceptions on risk, and a basis for constraints to distinguish autonomous from non-autonomous arguments. It should furthermore acknowledge the social embeddedness of individuals as do to justice to the social character of the development and impact of technology. The next chapter will be devoted to the explication of the concept of narrative autonomy that is considered to meet the above requirements.

For now it can be stated that demands following from the concept of narrative autonomy include that representations and perceptions of risk need at

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least accord with basic scientific rationality. This does not imply that laypeople have to provide scientific evidence to sustain their arguments. This cannot be expected from individuals (or groups) who lack resources to initiate relevant research. It does imply that their arguments supporting specific criteria for evidence of harm need to be scientifically tenable. Furthermore, moral arguments for evaluating a risk in the risk management phase should take the shared basic values within a society into account. In western society these can be summarized as equality, justice, respect for autonomy and non-malificence. Each of these values is characterized by the quality of overridingness over other values. A more elaborate discussion of this procedure and an argumentation for this procedure is presented in chapter three.

### 2.4.2. Public and political debates

To enable the three amendments suggested above, i.e. allow laypeople more influence on criteria for evidence on harm and on the aims of technological development, as well as the requirement of justification of arguments put forward, decision procedures in technological practice should have the character of public and political debates. They should be public when dealing with the issues concerning the representation of risk and political when decisions relating to the management of the risk are discussed.

Public debates allow individuals to exchange perspectives and arguments, something which the solitary exercise of medical IC does not allow. This part of decision procedures concerning risks does not necessarily lead to political consequences. It is meant primarily to uncover all the different perspectives concerning the representation of risk. Additionally it is intended to distinguish which arguments have a prima facie claim to be taken up as an argument in the political debate. Only autonomous arguments should be transported into the political debate.

The debate becomes political in nature once a decision on the management of risk is at stake. This question is political because it concerns decisions that can directly affect people. Such decisions will have societal consequences. In this debate the various autonomous arguments from the public debate should be assessed on their political tenability.

An implication of the wide-ranging impact of technological developments is that possibly not every individual that may be affected by a technological risk will

participate in the debate about its acceptability. It would be highly impractical to involve everyone in a public debate. In most Western societies democracy has been embraced as the way to ensure that everybody's voice is heard on issues that concern everybody. However, as explained in the introduction chapter, democratic procedures as they are now in most Western societies are not considered adequate to accommodate individual autonomy with regard to the acceptability of technological risks. I consider a public debate in which those who are really concerned about a specific risk can argue for their specific position as better suited to accommodate individual autonomy. This assumes that not every individual will feel compelled to participate in a particular discussion about the acceptability of risks. This should not be considered as undermining their autonomy, but as a necessary consequence of autonomous living. Autonomy is not about influence over each and every aspect of the society one is part of, this is too demanding for the individual. Rather, autonomy is served by societal structures that allow the individual to pursue the interests that are most important to her while she is able to trust others to take care of her interests in other areas in a reliable way.

These remarks do not necessarily imply that all disputes on technological risks will fall prey to the interests of defenders of extreme positions within that dispute. Although this might happen, the quality of arguments needs to be such that general societal interests are taken into account. So, even if people do not actively voice their concerns, their interests will not be ignored.

All the above about the desirability of a public debate and the critical review of arguments does not imply that I expect such debates to always lead to conclusive outcomes that are acceptable to everybody who is possibly affected by a technological development. I do expect, however, that such debates will sensitivize policies with regard to risk to a broader range of concerns than is currently the case. This might in turn impact the design of potentially risky technology to accommodate a broader range of concerns than is customary at present. How this should come about is expressed in the discussion of the case-studies in chapters 5, 6 & 7.

### **2.5. Conclusion**

The procedure of informed consent as employed in medical practice is insufficient to guarantee respect for individual autonomy in technological

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practice. Respect for autonomy in this latter practice requires three amendments as compared to IC. These amendments include: inclusion of laypeople in all three stages of risk assessment, a more thorough discussion of the necessity of technological developments, the need to justify any arguments in relation to the acceptability of technological risk. These amendments can be captured through formalizing decision procedures as public and political debates.

The need for these amendments relates to certain differences between medical and technological practice. With regard to identification and estimation of risks, a difference occurs in the variety in assumptions that underlie the representation of risks. This difference arises out of the relative coherence, closedness and autonomy that characterize medical practice compared to the heterogeneity and the vaguely defined borders of technological practice. This explains why respect for autonomy in medical practice is designed as a procedure that invites input from the layperson only at the third stage of the procedure.

With regard to the management aspect of risks, the main differences relate to the aims of both practices and the scale of impact of both practices. For various reasons, the aims of medical practice are less contested than that of technological practice. This implies that medical risks are generally more easily accepted than technological risks and that for procedures accommodating individual autonomy in technological practice more extensive debate is required than for medical practice.

The larger scale of technological practice requires that the concerns of many people have to be taken into account. This might be best achieved through the format of public debates. In these debates, demands should be imposed on the quality of the arguments of the participants as any decision on the acceptability of risk will have consequences for other individuals. Since respect for autonomy is of paramount importance, only those arguments that can be considered autonomous arguments deserve respect from other participants in public debates. What kind of criteria determine whether an argument is autonomously made, depends on the concept of autonomy employed. The next chapter is devoted to explicating the concept of autonomy that underlies this research and that is considered to be specifically apt to decision procedures concerning the acceptability of technological risks.

# 3 Narrative autonomy<sup>1</sup>

## 3.1. Autonomy in a highly technological society

### 3.1.1. A new concept of autonomy

What is a useful concept of autonomy in the context of technological risk? Historically, a myriad of accounts of autonomy have been developed, each with their own advantages and drawbacks. In this chapter I seek to develop a concept of autonomy that is specifically applicable to the modern human condition, characterized by an intense technological environment.

Existing, influential concepts of autonomy such as those conceptualized by Immanuel Kant, John Stuart Mill and feminist authors (see Meyer: 1989; Walker: 1998; Williams: 2004) offer useful starting points for such a concept. However, in the context of technological risks these concepts show some drawbacks. In this research a concept of autonomy is developed that builds upon aspects of these traditional accounts of autonomy, but that is intended to overcome the drawbacks of the traditional accounts in the context of technological risks.

The specific concept of autonomy developed in this research is narrative autonomy. Narrative self-understanding is central to this notion of autonomy. While developing this notion, I will draw much on the work of authors such as Marya Schechtman and Anthony Laden and I am indebted to many of the feminists' analyses of autonomy. My concept of narrative autonomy resembles that of Susan Williams (2004) but differs in some essential aspects that will be explained below.

The concept of narrative autonomy provides the basis to structure decision procedures on technological risks in such a way that respect for autonomy is accommodated. At the end of this chapter I will arrive at three main recommendations for such decision procedures.

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<sup>1</sup> An abridged version of this chapter has previously been published in Asveld (2008a), together with an abridged version of chapter 5

### 3.1.2. Requirements for a useful concept of autonomy

What is required of a concept of autonomy in the context of technological risk? I have given a basic, minimal definition of autonomy in the first chapter of this dissertation, namely autonomy is the ability to make and enact decisions according to one's moral framework. From this initial definition, some requirements can be derived for respect for autonomy in the context of technological risks. A useful concept of autonomy should offer a meaningful framework to substantiate these requirements.

As argued in the previous chapter these requirements for a useful concept of autonomy are:

- a) it should offer a basis to accommodate diversity
- b) it should incorporate the social embeddedness of individuals
- c) it should offer a basis to put constraints on arguments put forward in decision procedures on technological risks

With regard to a) numerous different perspectives on the character and acceptability of technological risks exists, many of which are viable. In order to respect autonomy, it is necessary to acknowledge these different perspectives.

With regard to b) individual human beings are ultimately social entities. We are constituted and determined by the social structures of which we form a part. A useful concept of autonomy should address the relations between the social and the individual aspects of persons.

With regard to c) claims about the acceptability of risk will affect other individuals. To ensure that the autonomy of each individual is protected, a certain quality may be demanded of the divergent arguments for them to carry any moral weight within decision procedures on technological risks.

The existing accounts of autonomy formulated by Mill, Kant and feminist authors offer useful starting points for conceptualizing these requirements. Mill's conception of autonomy is very much an effort to accommodate diversity (requirement a). Kant's concept of autonomy is basically a constraint on autonomously made arguments (requirement c). These two concepts are powerful and resilient, but they have also been criticized as presupposing a rather isolated individual. Originating in this criticism, feminist authors have introduced concepts of autonomy that incorporate social relations (requirement

b). Although the qualities of these three existing concepts are useful, some drawbacks remain. I will discuss the three concepts in turn.

### **3.2. Traditional accounts**

My discussion of existing accounts of autonomy is necessarily limited to a very rough consideration of what can be seen as notions underlying much of our contemporary thinking about autonomy. I will focus on those aspects of these traditional accounts that are relevant to my purpose. I do not intend to start a discussion on the general merits of these accounts, but merely on salient aspects in relation to decision procedures on risks. I will start with Millian autonomy and diversity, followed by a discussion of feminist accounts of autonomy and social embeddedness and close with Kant and constraints on autonomy.

#### **3.2.1. Millian autonomy**

Mill can be understood as an ardent defender of respect for diversity. He was especially concerned with the protection of external autonomy, i.e. the freedom to do as one deems best without interferences from other parties, and this can be understood as one of the most important aspects of his legacy. I will consider this aspect of Millian autonomy especially, since it is an important influence on our current dealings with technological risks. The (neo-)liberal focus on the protection of external autonomy, inspired by Mill, has led to a disregard of internal autonomy, i.e. the actual skills and, mental and emotional, abilities required to determine what oneself deems best and to act upon that. As will be argued here, this disregard has undesirable consequences.

I use the term external and internal autonomy here to indicate aspects of autonomy that have previously and famously been termed. positive and negative freedom by Isaiah Berlin (1958). However, I've chosen to stick with external and internal autonomy because these terms most clearly indicate the concern that directs this research, namely respect for autonomy. Negative freedom or external autonomy concerns factors that are external to an agent (see Carter: 2003). Freedom of speech is an example of negative freedom. It effectively restricts the range and kind of impositions to which a government can subject its citizens. Citizens need not make active use of this freedom in order for it to be effective. Negative freedom, or external autonomy, is a description of the social space we are granted by our environment to act upon our personal autonomous choices



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(see Berlin: 2002b, 169). As Berlin puts it: “I am normally said to be free to the degree to which no man or body of men interferes with my activity” (see Berlin: 2002b, 169).

Positive freedom or internal autonomy refers to the ability to act autonomously as determined by factors that are internal to an agent (see Carter: 2003). This ability can be conceptualized by questions such as: Do you have the mental and social resources to be the person you want to be? Can you direct your life in a meaningful way? Can you master yourself? As Berlin describes this aspect of autonomy: “I wish, above all, to be conscious of myself as a thinking, willing active being, bearing responsibilities for my choices and able to explain them by reference to my own ideas and purposes” (see Berlin: 2002b, 178).

These two aspects of autonomy or freedom may appear not to be too far apart. As Berlin already indicated:

“The freedom which consists in being one’s own master, and the freedom which consists in not being prevented from choosing as I do by other men, may, on the face of it, seem concepts at no great logical distance from each other – no more than negative and positive ways of saying much the same thing. Yet the ‘positive’ and the ‘negative’ notions of freedom historically developed in divergent directions, not always by logically reputable steps, until, in the end, they came into direct conflict with each other” (see Berlin: 2002b, 178-179)

A focus on respect for either internal or external autonomy may lead to diverging policies. A focus on respect for internal autonomy might, for instance, lead to the imposition of a specific lifestyle by authorities, as this is supposed to support internal autonomy best for everyone, whereas respect for external autonomy might lead to far-ranging toleration for a wide diversity of lifestyles (see Berlin: 2002b). In this research it will become apparent that respect for these two aspects of autonomy also clash in policies that direct decision procedures on the acceptability of technological risk. The clash between them will be most prominently illustrated in the case study presented in chapter 4 concerning a trade-conflict on the risks associated with GMOs.

Policies in which respect for external autonomy is of paramount importance can be traced back to a Millian perspective on autonomy. Mill put respect for external autonomy at the core of his political philosophy (see Mill: 1859/1972). He was concerned with achieving well-being for as many people as possible. The freedom to do what one wants without external interferences is central to that goal, according to Mill. He held a strong belief that the creativity of the

individual should never be curtailed, that critical abilities and rational dissent should be stimulated, even at the cost of individuals ruining their own lives (see Berlin: 2002a). Individuals themselves should determine what is good for them, as this will eventually contribute to the greater good. “Mankind are greater gainers by suffering each other to live as seems good to themselves, than by compelling each to live as seems good to the rest.” (see Mill: 1859/1972, 76)

The Millian view and any policies derived from this view have led to a preoccupation with the negative aspect of freedom, i.e. the freedom to do as one sees fit without interference from other parties. According to a general liberal approach to autonomy inspired by Mill, freedom may be limited solely by consent from the agent whose freedom is limited or for the sake of protecting other individuals or society at large. This latter principle is known as the harm principle. This principle states that possible harm to third parties provides a legitimate reason, for the state, or other individuals, to restrict the freedom of an individual (see Wolff: 1996, 123-124, Held: 1987, 101).

Interference with someone else’s liberty can never be justified with concepts of the good life, according to liberal, Millian theory. Such concepts may not be shared by the person(s) whose liberty is curtailed. Hence, they would unjustifiably limit external freedom. A member of a religious group for instance, who would demand that all women wear dresses or skirts that fall below the knees, because women in trousers or shorts offend his religion would not be heard in a liberal society. One cannot impose one’s visions of the good life on other people. However, the concept of harm itself can also be contested and questioned considering various perceptions of the good life. What I deem harmful may not appear harmful to you. It may be questioned for instance whether economic inequality is a harm or just a consequence of individual freedom (see Held: 1996, 102). The requirement for a neutral justification of interference is interpreted by Gerald Gaus as a requirement for conclusive justification (see Gaus: 1996), implying that interference is justified if all relevant actors can reasonably be expected to consent to the reasons underlying that interference.

The struggle to defend external autonomy as much as possible has led to the marginalization of the internal aspect of autonomy within liberal theory. This internal aspect of autonomy is also referred to as positive freedom. The internal aspect refers to our ability to act autonomously as determined by factors that are internal to an agent (see Carter: 2003). I perceive internal autonomy to be

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directly related to personal identity. As will be argued more extensively below, personal identity provides the moral framework on which individuals rely when making autonomous decisions. As argued in the previous chapter, this framework is highly relevant in the context of evaluating risk. Personal identity is furthermore related to one's social identity: the place one has in society and one's related skills and capacities.

With regard to moral frameworks and the evaluation of risks; it is difficult to exclude references to a particular concept of the good life from decision procedures on the acceptability of technological risks. As argued in the previous chapter, representations of risks derive from what we would term 'world views'. The world view of an individual (party) provides the framework of reference within which risks are identified. Representations of risks necessarily rely on such frameworks of reference as they are basically social constructs. Such representations cannot be considered neutral, some of the parties will perceive a lack of, or low, risk in a certain situation, while others may perceive the risks to be high.

The worldviews from which representations of risks derive are part of the identity of individuals. They constitute the moral frameworks that guide individuals in decision-making. Hence, such world views should be understood as part of the internal aspect of autonomy. To demand a neutral representation of harm might eventually undermine the protection of freedom because it does not acknowledge the internal aspect of autonomy. This point will be illustrated in the next chapter in a case study on the trade in genetically modified organisms.

With regard to social identity, many feminist writers have already convincingly argued that the liberal focus on external autonomy disregards the social embeddedness of individuals and the ensuing differences between individuals (see Williams: 2004, 61-68). Each individual is a product of the social relations in which she develops herself. These relations and the position of the individual within these relations create (often valuable) differences between individuals.

An important difference between individuals resulting from their personal identity is a difference in access to knowledge and knowledge production, and relatedly a difference in capacity for producing convincing argumentation for or against policies etc. within the public domain (see Bergin: 2002, 198). Producers of technological developments generally have more access to scientific resources

than laypeople who oppose such developments. If protesting against, or promoting, interference with individual liberty requires support of good arguments, such as evidence of a possible harm, then those parties with access to the means to provide scientific evidence in support of their claim have a great advantage over parties who lack access to such resources.

Concluding, in a concept of autonomy that is applicable to decision procedures on technological risk, the Millian respect for diversity should be maintained by incorporating the notion that interferences with freedom needs to be justified. In this way, protection of external freedom is maintained, however, the basis for this justification will not consist of conclusive justification, requiring that an interference is justified if all relevant actors can reasonably be expected to consent to the reasons underlying such interference. This requirement has two consequences that are incompatible with respect for the internal aspects of autonomy for two reasons. One, some perspectives on risk cannot be justified to all actors, while they should nonetheless be accommodated taking into account the autonomy of the parties who put forward such a perspective. Two, not all actors are equally able to support their perspective on risk due to their social identity and ensuing capacities. In this research I will develop a different basis for justification of interference with individual freedom. This approach will be explained extensively below. In this new concept of autonomy I will explicitly consider the personal identities of individuals and their capacity to provide evidence for harm. Furthermore, conceptions of the good life will not be excluded from decision procedures on the acceptability of risk. How these elements will be incorporated into the concept of narrative autonomy will also be discussed.

### **3.2.2. Feminist concepts of autonomy**

Feminist authors provide concepts of autonomy in which the social embeddedness of the individual is central. Feminist critiques on Millian concepts of autonomy have underscored some of the problematic aspects identified above. A problem with this general feminist approach is that it lacks grounds to assess individual judgments critically.

A main allegation of the feminists against traditional notions of autonomy and self-determinacy is the exclusion of female perspectives. Kantian and Millian understandings of autonomy offer little room for dependencies, such as care-

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relations like mother-child relations, and emotional ties, such as those between spouses, that may interfere with a straightforward, shrewd personal plan for pursuing one's goals or reasoning in a detached, universalizable manner (see Meyer: 1989; Walker: 1998; Williams: 2004). The Millian and Kantian accounts are therefore alleged to be male-centred as they take a male person, who is relatively unburdened with direct care-relationships as to be typical for all individuals. Feminist theory, in contrast, places paramount importance on the relational aspect of autonomy, for both men and women. Social relations determine what value the individual gives to a particular consideration. In his frame of reference, he is ultimately defined by his social surroundings and by the relationships he forms (see Meyer: 1989).

Moreover, the capacity for acting autonomously itself is considered to be a product of social relationships from the feminist perspective. It is in a specific social context, for instance, in the shielded warmth of a family that children learn to be assertive, to articulate their desires. We need such social relationships to become autonomous persons (see Williams: 2004). Our social identity, thus, constitutes our capacity to act autonomously, or, put differently, we are positively free because we are social creatures. In the Millian and Kantian perspectives, social influences appear to constitute a barrier to autonomy rather than an enabling factor.

Relationships however, can be flimsy and treacherous and are constantly subject to change. Understanding autonomy as a product of such contingent influences leaves little firm moral ground on which to base the concept itself. The general feminist approach to autonomy may lead to a relativistic point of view that eventually leaves the feminists empty-handed. If the make-up of freedom, both positive and negative, depends on contextual characteristics, criticism becomes problematic. The more detached Kantian and Millian approaches provide a ground for such criticism because they maintain certain values irrespective of the context.

This is also acknowledged by many feminists. Some fundamental values cannot be overruled by the moral weight of relationships (see Meyer: 1989). These fundamental values are thus not dependent on contextual characteristics and hence do not suffer from the deficits of relativism. A woman who is submissive towards her husband and gives up her independence to gain his love, would not be considered autonomous in feminists' theories, even if she makes this choice willingly and after considerable reflection.

The feminist notion does not fully explain why some decisions should be considered more autonomous than others. The main motivation appears to be a revolt against the historical disadvantaged position of women in most cultures. However, it is not entirely clear how this should be intrinsically linked to autonomy. One may very well be free and autonomous, and consciously choose to be in a submissive role in a relationship, especially if we consider the social context and relationships as constitutive of autonomous behavior. Different social contexts may lead women to embrace widely diverging courses of actions of their free will. Why some courses of action ought to be excluded from the set of autonomous actions remains unexplained in the feminist approach.<sup>2</sup>

An additional deficit of the relational model is that the strong focus on relationships does not fully describe how autonomous actions come about. Even if the moral importance of certain relationships is recognized, it may still leave open the question of how one should act on them. We might for instance attach different weights to relationships in different contexts for different persons (see Christman: 2004, 145). For one woman it is unthinkable to leave the care for her child to a childcare institute, whereas for another woman this seems the only right course to take. There is no indication that either of them loves their child more or less. They solely interpret the obligation that attaches to this relationship in a different way. Additional considerations that stem from each woman's personal history may be of influence. For instance, each of them will have had a specific example from their own mothers, which may compel them to develop a specific strategy in their own lives.

Besides being socially determined, an individual is also a unique person who cannot be reduced to social relations alone. To claim that individual decisions are made primarily with reference to surrounding social relations lacks attention for the uniqueness of each individual. The format of feminist autonomy is strongly motivated by a struggle for social justice, which necessarily leads it to be focused on group characteristics, instead of the specific needs and moral outlooks of individuals.

As a conclusion it can be stated that the feminist concept of autonomy is lacking in that it sets substantive demands on what decisions can be considered autonomous, which are not entirely compatible with its focus on social context

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<sup>2</sup> Willams (2004) describes various attempts of feminists to maintain the force of deconstructive analysis without falling into the trap of relativism. As she shows, none of these attempts are entirely satisfactory.

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and relationships. The feminist incorporation of the social embeddedness of individuals in understanding autonomy will be maintained in the narrative concept of autonomy. The narrative concept will, however, also offer a ground to distinguish between autonomously and non-autonomously made judgments.

### 3.2.3. Kantian autonomy

In contrast to feminist perspectives, Kant offers a concept of autonomy in which individual moral judgments are central. In this concept, constraints on those judgments are of paramount importance. I want to discuss a general approach to autonomy of which the Kantian view is the most prominent version, in which autonomy is equated with a detached, highly rational outlook. A problem with this approach is that it fails to take into account the importance of context for meaningful moral deliberation.

Human beings are their own ultimate lawgivers according to Kant. They require no external authority to advise them what to do to do good. This claim marked a radical shift from previous widely shared perceptions maintaining that ordinary people were incapable of knowing what morality requires of them. In these views, most people ought to be told how to behave in a morally desirable fashion (see Schneewind: 1998, 509). Kant's position formed a strong break from such more hierarchical positions.<sup>3</sup>

As each individual possesses a rational faculty, each individual is capable of understanding what is morally required of him, Kant stated. As such, each individual should be able to formulate the laws that should guide his behavior. Such laws should transcend the contingencies of particular situations: they should be universally applicable. Only when such universalizable laws motivate us can we be considered free and autonomous because then we are undetermined by external contingent influences such as particular individual identities or situations (see Schneewind: 1992, 320-321).

Autonomy in the Kantian sense is distinctly different from Millian or feminist concepts of autonomy. "For Kant autonomy is not relational, *not graduated, not a form of self-expression*; it is a matter of acting on certain sorts of principles, and specifically on principles of obligation" (see O'Neill: 2002, 83-84). Kant formulated guidelines for autonomous behavior, which would lead to

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<sup>3</sup> He was not alone in taking such a position, another distinguished philosopher who defended the value of the moral insights of ordinary people was Thomas Reid (18<sup>th</sup> century)

actions that could be accepted by everyone. The value of such actions does not depend on contingent, contextual influences. One principle, the *categorical imperative* should direct every individual's reflections when considering what course of action to follow. The relevant formulation of the categorical imperative is: "Act only according to that maxim by which you can at the same time will that it would become a universal law." (see Kant: 1785). This formulation is also known as the Formula of Autonomy. The categorical imperative is the only principle that is intrinsic to moral lawmaking. Any external principles constraining the formulation of laws would make lawmaking unfree since then laws would be contingent upon these external principles. This approach will allow the individual to perceive adequately what the moral law requires and to invent it for herself, according to Kant. The categorical imperative is the building block for free, autonomous lawmaking for individuals (see Korsgaard: 1984, 81).

The Kantian view has been criticized for various reasons. This criticism has been most forcefully formulated by Bernard Williams (see Williams: 1981, ch.1). As Williams states, a theory of morality cannot be accurate if it excludes the specific characteristics of individuals' lives as motivating factors, because exactly those specific characteristics convey a sense of moral meaning to specific actions and choices. Kant's preoccupation with universalizability requires the individual to neglect those aspects of his life which render it especially (morally) meaningful.

Firstly, Kant's concept of autonomy depends heavily on reason and leaves little room for factors such as emotions and desires which make up an important feature of human behavior. If autonomy is about freedom, its elaboration should not depend too heavily on the exclusion of what are, for most people, very real and strong motivating forces. Emotions constitute a large part of who we are and what we want (see Nussbaum: 2001; Roeser: 2002).

Secondly, Kantian autonomy requires the autonomous individual to act in a detached manner, i.e. to abstract as much as possible from the contingencies of her own historical and social position. However, precisely these contingencies of our specific place in society and in history make us individuals. These aspects of our being give us an identity. It is this identity that enables us eventually to deal with problems of a moral nature and it is our social embeddedness that supports our moral reasoning. We often derive our moral categories from the social context we habituate.



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To come to ethically appropriate decisions, context often plays an influential part. In some cultures, when someone is terminally ill, people around him will not inform him of the graveness of the situation. Informing a person about the approach of death, is, in such a culture, considered a sign of abandoning this person. As long as his family keeps the seriousness of the disease a secret for the patient, they carry his suffering for him (see Gordon & Paci: 1997). The maxim in this case: “withhold information to spare a person’s feelings”, cannot be universalized. We cannot avoid telling people they will be fired or that we want to end a relationship. In many countries, we even think it is a sign of respect to give full disclosure of information. In that way, the informed person can make his own, autonomous decision. We are not patronizing him.

In this particular case however, the cultural context indicates that it is cruel to inform a patient of her condition. It would undermine the personhood of this patient as he is ‘given up’ on and thereby socially declared dead. In this context, personhood is conceptualized differently than in some other contexts. The moral categories relevant in this particular context dictate another approach than would be desirable in another moral context. To approach such a situation in a rational, detached manner, acting on universalizable principles, would convey much disrespect to the patient and his cultural background. Moreover, it would be very difficult to approach such issues in a rational, detached manner. Moral reflection requires a set of moral categories, such as a concept of personhood. Which concept of personhood is employed has consequences for other moral categories such as rights and obligations. It is the social context that conveys these moral categories. The appropriateness and the origin of moral judgments are context dependent.

I do not mean to claim that morality is always entirely contextual. Some cultural practices may be deemed morally undesirable even if they form an important part of the local cultural heritage. The point is that the choice regarding the right maxim, or between conflicting maxims, is often determined by emotions and contingencies particular to a given situation. Identifying what constitutes ‘unnecessary harm’ as in the above example is ultimately a contextual affair. Such aspects of our experience are often indispensable for arriving at a moral judgment concerning a given situation.

A Kantian approach to autonomy leaves little room for the importance of context and the diversity that ensues from it. However, as said before, the idea of using constraints to distinguish autonomously made judgments from non-

autonomously made judgments is appealing. To avoid the problems mentioned above, the concept of narrative autonomy will contain constraints that are distinctly extrinsic to lawmaking. This implies that these constraints derive from the context in which the individual is socially embedded. In this way the importance of the context for meaningful moral deliberation is incorporated in the concept of narrative autonomy. How this will come about is explicated in the following section.

### 3.3. Narrative autonomy

The concept of narrative autonomy integrates Millian respect for diversity, the feminist concept of social embeddedness and the Kantian concept of constraints on autonomy, while aiming to overcome the weaknesses of these accounts. This is done by putting the notion of narrative identity central to autonomy.

Respect for diversity is embodied in the recognition of the existence of diverse individual perspectives, as each person has her own unique narrative identity. This identity forms the basis of autonomy and should be respected.

Social embeddedness of individuals is captured by the relation between personal narratives and social-cultural narratives. Each individual narrative is framed by surrounding social-cultural narratives. These social-cultural narratives provide the individual with tools to construct a unique, personal narrative, whether the individual complies with or digresses from these social-cultural narratives.

Narratives are only considered to be identity constituting and hence to sustain an autonomous individual if they live up to two distinct constraints. These constraints are formulated as the Reality Constraint and the Articulation Constraint, based on the work of Marya Schechtman (1996). Their actual meaning is derived from social-cultural narratives that make up the context in which the individual is situated. This is done through the concept of form and content features of identity, based on the work of Anthony Laden (2002).

These features of narrative autonomy lead to specific recommendations for decision procedures on technological risk. The following sections contain an elaborate explanation of the concept of narrative autonomy, followed by an explication of the recommendations. These recommendations will be applied in the case-studies (chapter 4,5 & 6) to investigate how they work out in practice. The recommendations will then be evaluated in chapter 7.

### 3.3.1. Identity and internal autonomy

How is identity related to autonomy? Identity is fundamental to being autonomous in two ways. One, identity offers a framework that enables critical reflection on oneself. Identity is the conception of who one is and who one wants to be. Two, one's identity determines one's social resources, such as specific capabilities and social status. These social resources are important elements of individual autonomy.

With regard to the issue of reflection, we may recall that autonomy consists of both an internal and an external aspect (section 3.2.1). The internal aspect of autonomy refers to the competence of the individual to actually act according to her own moral convictions. Internal autonomy as such involves a reflection on one's actions, the outcome of which effectively determines those actions. If one acts on a whim, this is not an autonomous action.

Authors such as Harry Frankfurt (1971) and Gerald Dworkin (1988) have referred to the process of reflection on one's initial preferences as the formation of second-order preferences or desires. First-order preferences consist of our initial desires and motivations to act. When these are subjected to critical scrutiny, second-order preferences arise. Consider for instance a woman who is confronted with strong first-order desires. She may be swept away by her attraction to another man, while she is married. If she is an autonomous person, she will reflect on this attraction and consider how to react on it. The outcome of this reflection, whether she agrees with herself that she wants to want to have an affair or that she does not want to want to have an affair, are the second-order preferences. These second-order preferences are about actually identifying (or not) with the first-order preferences.

I interpret this process as the content of internal autonomy. Following Charles Taylor (1985, 1989) and Christine Korsgaard (1992) I consider identity to be of paramount importance for this process. Identity provides the framework with which second-order preferences are formed. Positive freedom is associated with identity. To have a sense of oneself, to understand oneself in a particular way, contributes to knowing what one wants, how one wants it and how one can achieve it. Without identity, there is little use for positive freedom.

Reflection on oneself involves having an identity. I understand an identity as usually comprising a variety of roles. A person may for instance be a parent, an employee and a partner in a marriage. An individual may have all kinds of ideas about how she should fulfill these different roles. Two mothers in different

cultures may for instance each perceive themselves as good mothers and carry a similar sense of the obligations that connect to good motherhood, but they may interpret this differently. The obligation to feed a child well, for instance, will lead to different practical actions in different parts of the world. For the individual, the actual practice and the connected obligation may not be recognizable as separate entities. The practical action and the moral value are inextricably intertwined.

Identity provides a moral framework within which oneself and other people are judged. The moral character of this framework may not always be easily discernible. Norms and values may be intertwined with other elements of an identity, such as cultural interpretations of specific roles. This moral identity framework contains the resources with which a person assesses her own initial preferences. Consider again the married woman who feels attracted to a man who is not her husband. She would like to venture into a relationship with this other man; but probably she feels a very strong, conflicting desire to be a good and faithful wife. When she considers these two desires she may end up deciding that she sees herself more as a good wife than as an adventurous mistress. Although she has a desire to be both, her identity, the way she sees herself, compels her to remain loyal to her husband.

Aside from offering a framework to enable reflection, identity also comprises the concept of social resources, such as skills, status and affluence. In the approach advocated by Amartya Sen and Martha Nussbaum, individual autonomy is not served solely by respecting individual rights, it is also served by assuring that each individual is capable of fulfilling elementary aspects of life, such as obtaining sufficient nourishment. Beyond these basic needs opportunities for economic development can also be considered relevant (see Nussbaum: 2000; Sen: 1985). Additionally, opportunities for cultural and mental developments may also be relevant.

Whether an individual is indeed able to meet such needs and in what manner, may depend to a large degree on his social position. A wealthy individual may have better opportunities than a poor individual. Such differences between individuals are to some degree undesirable, e.g. when they imply a large difference in income. However, in other respects, differences between individuals are highly desirable. They can be a benefit of all. This is especially true for specialization. Modern societies are characterized by division of labor. Such professional specialization is a prerequisite for autonomy more

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than it is an impediment for autonomy. To be the person we want to be and to fulfill our life projects, we cannot allow our attention to be diverted too often by other issues that are less central to our life plan and our aspirations as individual. Should the individual be required to spend time and energy on the numerous technological risks that surround us, he would be unable to deal adequately with his family life, his main job, friends and other activities. It is precisely because a network of highly skilled experts exists that is concerned with providing a safe environment for the individual, that he can focus on matters he really cares about.

Hence, differences in skills, social status and access to resources need not necessarily undermine the autonomy of individuals. They can in many cases be regarded as important elements of one's identity, elements that convey a sense of uniqueness and purposefulness. To occupy a certain niche within society, in a professional, cultural or economic sense will add to understanding oneself as a self-reliant individual.

I consider social resources to be part of internal autonomy as they determine the individual's capability to be the person she wants to be. Any barriers the individual experiences in obtaining the social resources she desires are related to external autonomy, insofar as this depends on factors external to the individual and not on, for instance, weakness of will. Such factors may include discrimination, oppression and exclusion. However, in general, divergence in capabilities should be understood as elements of positive freedom or internal autonomy because they provide the individual with an identity and specific skills and resources to find her way through life.

### 3.3.2. Narrativity and identity

An identity can be conceived of as a narrative (see Schechtman: 1996; Ricoeur: 1991; Taylor: 1989).<sup>4</sup> The narrative of one's life gives meaning to individual

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<sup>4</sup> Philosophically, identity is a multifaceted concept, which combines many different questions, such as what makes an entity a person and what is the moral relevance of identity. The major issue dominating the debate on personal identity is the reidentification issue. This concerns the question: What makes someone the same person at two different points in time? With regard to autonomy however, the most important issue is not *whether* a person has changed into someone else, but *how* a person has changed and what this change means for the person. What I am interested in is what Korsgaard (1984) terms 'practical identity': a description of yourself that gives rise to moral reasons and obligations (p.83/84). This is different from a

events and makes one's actions intelligible to oneself and to others (see Schechtman: 1996, 94-95; Taylor: 1989, 48). Seemingly anomalous acts can be given meaning within a certain narrative. The logic that connects these events is the logic associated with the unfolding of the life of a person. This logic needs to be coherent enough to sustain a well-defined character (see Schechtman: 1996, 97).

I imagine this would work out as follows in the example of the woman in doubt about her attraction to another man. She might try to understand her attraction to another man by reflection on her life and past experiences. She may construct a story that links separate events in her life. For instance: when she was young, she always wanted to be an actress. She did venture in to acting, with some modest success. When she met her husband she gave up acting, being the loyal, supporting wife she is, but the desire to be admired as an actress is still lurking. When another man comes around who appreciates her talent for drama, she feels understood by him. Seeing herself as she does through this narrative, she decides not to have an affair with this man she's attracted to, but instead to take up acting again.

A narrative helps us to reflect on ourselves and understand ourselves. It offers a moral framework. As Taylor (1989) describes it: identity provides the moral horizon on which we orient ourselves. We are in a constant flux between constructing this framework and interpreting separate events. Each of us does this in a highly personal manner. We all have our own story to tell. This does in no way imply that all narratives are equally valid. People can construct narratives that are false. Criteria exist to determine the quality of a narrative.

According to Schechtman (1996) two constraints can be imposed on personal narratives. One is the Reality Constraint (p. 119) and the other is the Articulation Constraint (p.114). The Reality Constraint requires that an identity-constituting self-narrative fundamentally cohere with reality. Errors may occur in the recounting of facts, and in the interpretation of facts and these should be avoided so as not to deceive ourselves and misunderstand ourselves.

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description of the nature of the links between person time-slices, which do not necessarily give the individual moral guidance on how to act. The narrative account of identity provides a description of identity that is all encompassing. It comprises the criterium of continuity, it describes the development of moral frameworks and expounds the relations between a person's self and environment.

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However, especially with this latter error, it is not always obvious whose interpretation of a given event is the right one, although some interpretations can be closer to the truth than others. “Fundamental agreement on the most basic features of reality is required for the kinds of interactions that take place between persons to be possible”(see Schechtman: 1996, 119). I will return to this point later (section 3.3.3).

The Articulation constraint requires that a person is able to explain what he does and why he does it, both to himself and to others. Of course, there are elements of oneself that determine one’s actions that one is not aware of or cannot fully articulate. These elements are also considered part of a person’s identity by Schechtman, but less fundamentally so than the elements a person is able to articulate explicitly. However, a certain degree of articulateness is required to consider a person in charge of his identity and hence to be autonomous, although this does not imply overall transparency about one’s motives as this is almost unattainable (see Schechtman: 1996, 117). As long as the individual can provide a personal narrative of herself that is overall intelligible and that gives meaning, it is unproblematic that some elements of someone’s motives remain obscured. What is most important about the narrative understanding of oneself is that the guiding principles and moral convictions are articulated, according to Schechtman (1996, 116).

### 3.3.3. Cultural, social narratives and individual narratives

Articulation of one’s narrative identity and intelligibility of oneself and to others is strongly related to the larger cultural narratives that also shape our identity. The narratives we construct of ourselves have an immediate relationship with the cultural and social narratives that surround us. An identity exists always, to a considerable extent at least, by the grace of other people’s recognition of this identity. As Schechtman (1996) states: “To enter into the world of persons an individual needs, roughly speaking, to grasp her culture’s concept of a person and apply it to herself. It is this recognition which leads to the constraints on an identity-constituting narrative – to be identity-defining an individual’s self-narrative must conform in certain crucial respects to the narratives others tell of his life”(see Schechtman: 1996, 95).

This implies that an identity constituting a narrative is both extremely subjective, as no-one else could recount the story of your life, and at the same

time intersubjective, in the sense that other people must be able to recognize the narrative an individual has constructed of herself. The personal narrative and the interpretation others have of an individual's narrative need not coincide totally, but as Schechtman states in the above quote, they 'must conform in crucial respects'. What is crucial is indicated by the constraints expounded above: the Articulation and Reality Constraint. I will first discuss the Articulation Constraint. Then I will discuss how this Constraint poses restrictions on individual constructions of identity in section 3.3.3.2 with reference to form and content features as proposed by Anthony Laden (2001). Section 3.3.3.3 is devoted to the Reality Constraint and its specific form and content features.

### **3.3.3.1. □ Articulation constraint**

With regard to the Articulation Constraint, there are two ways in which good narratives should adhere to criteria set by the social context. One, the narrative should be coherent and intelligible (see Schechtman: 1996, 98) and two, my addition: the narrative should make use of concepts that are accessible to other people, and are used in a way other people should be able to understand.

With regard to the first criterion: if someone acts in a remarkable way, 'out of character', a good narrative should be able to make sense of such a deviant act. A narrative that is unintelligible to others is not an identity-constituting narrative. Coherence requires that separate acts can be linked in a meaningful fashion. Of course, this criterion should be dealt with in a flexible way, as there are numerous different styles of narratives conceivable. However, the assumption is that in principle, the structure of all narratives overlaps substantially such as to make recognition by other persons likely; however exotic the actual narrative may appear to be. This overlap will be less between members of different cultures but still substantial enough to understand each other. In any case, concerning the construction of personal narratives the most important social actors will be persons who are situated in the same cultural context as oneself. The main objective of this criterion, in a social context, is to avoid insincere claims to the right to be respected in one's autonomy.

Sometimes 'hidden elements' in a person's motivations may be crucial to a person's behavior, without this person acknowledging this. An individual may be driven by resentments or passions in an unconscious way. If a reference to such unconscious forces is needed to make a person's behavior intelligible, then they should be understood as part of a person's self-narrative, even if the person does



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not acknowledge these elements of his self-narrative. However, according to Schechtman, such 'hidden elements' of which the individual himself is unconscious should be considered less his own than those elements of his narrative that are articulate and on which he does have a grasp. The tension between the articulate and inarticulate aspects of one's personal narrative become very pressing in a political context such as deciding on the acceptability of technological risks. I will elaborate on this point in the section on recommendations. This issue will be further illustrated in chapter 5 where the debate on mass-vaccination programmes is discussed.

With regard to the second criterion: I think that to be intelligible to others, and also to ourselves, we need frameworks of meaning that transcend the individual's perspective to refer to when constructing our own identity. These overarching frameworks give meaning to individual lives. They provide a common language that enables communication about ourselves (see Taylor: 1989, 38). Not everybody wants to get married, but when discussing our individual preferences we immediately get an impression from a person when she reveals her ideas on marriage.

Even when deviating from such overarching narratives, these narratives are still central in constructing the identity a person has of herself. The person is then defined by what she is not. "I am not a silly decent boring housewife." Such a negative construction will however not be sufficient for understanding oneself and explaining one's actions to others. One can insist that one is not a this or a that, but without providing any ground for such an identity, it will not provide much intelligibility to other persons. The availability of alternative cultural narratives provides a great help when constructing one's personal narrative and in making oneself intelligible to others. The narrative of 'boy meets girl' is for instance supplemented by narratives such as 'boy meets boy', 'girls meets girl', 'girl meets many boys', 'boy meets girl and then another girl'. The same values, such as for instance loyalty, may be present in all these narratives, only in different interpretations.

Narratives are a means to express certain moral convictions. They express certain values in a specific way, thereby prescribing how one should adhere to a particular value. The diversity of narratives can offer a diversity of interpretations of values. These values may not be very explicit and therefore not always very clear. Narratives will often shape and express individual and cultural moral outlooks.

The availability of different (sub cultural) narratives and the space to construct unique, individual narratives is important for autonomy. The existence of different narratives leads an individual to reflect on his personal wishes and preferences and to make certain choices. It shows the possibility of an alternative lifestyle, which is equivalent to the possibility of understanding oneself in a certain way.

A cultural narrative can be oppressive and exclude other narratives. If the dominant narrative is, for instance, that of heterosexual love and this is so strong that it excludes other narratives, someone with homosexual preferences will find it very hard to construct his narrative and his identity in a satisfactory way. In this sense the availability of multiple narratives helps one to construct one's identity. One's personal narrative is constructed from available cultural narratives. These narratives help the individual to reflect on the choices he makes as they offer moral frameworks and prescriptions for how to act. We are probably all in a continuous process of constructing our identities. A constant tension exists between individual narratives and larger, surrounding narratives.

We need shared cultural conceptions to understand ourselves and make ourselves understandable. However, not all aspects of identity need always be coherent with surrounding social-cultural structures to be credible and worthy of respect. If this would be the case, cultural or political developments would be stifled as people would be unable to re-invent themselves or to question persistent dominant stereotypes. Individuals may deviate from dominant narratives in the roles they play or the way they perceive reality.

Some aspects of identity are more open to interpretation than others, they leave more room for a specific individual perception, without undermining the communicative value or the credibility of identity. Some basic features of available roles are indispensable. To be a mother, one has to have (had) a child. But, to be a mother, one does not need to have given birth as there are other ways of becoming a mother, i.e. adopting a child. To be considered a homosexual, one needs to have homosexual feelings: but to be a homosexual, one need not lead a promiscuous life, although for some homosexuals, as for some heterosexuals, such a life is part of their (homosexual) identity. This difference between indispensable and flexible aspects of identity will be explained below with reference to form and content features (see Laden: 2001)

### 3.3.3.2. Form and content features

Laden (2001) puts forward the concepts of form features and content features of identity (p. 108), which may be helpful distinctions when considering the tension between individual and larger cultural and social narratives. In my discussion of these form and content features I stay close to Laden's conceptualisation. The way I illustrate and apply these features is my own. According to Laden, form features of identity are always externally dictated whereas content features can, but need not be, externally dictated. Externally dictated in this context implies: socially constructed in such a way that it cannot be altered easily by an individual. In contrast, content features of identity depend specifically on the interpretation of the individual.

“(...) the content features of an identity might vary widely without the identity itself having changed. They can, in this sense, be contingent features of the identity they characterize. Form features, however, derive from the place a given identity occupies in a more complicated, social system. The form characteristics of an identity are determined by the part it plays, and by what is required of someone playing that part, within a larger social context.” (see Laden: 2002, 108)

I think the concept of marriage nicely illustrates the difference between form and content features: of what it implies in social interactions to be married. Important aspects of form features, are for instance, the legal obligations that exist in a marriage between husband and wife. Content features pertain to how marriage and its accompanying values are interpreted by a specific couple. The form features are mainly social in character, whereas the content features are primarily private in character. However, private aspects of identities are to a substantial degree determined by form features, while form features are influenced by private aspects of ones identity. The effects these features on the identity of the individual will vary per situation and per individual.

Both form and content features of an identity are subject to change over time, but the form features less so than the content features, as Laden states (2002, 110). Again, I would like to illuminate these features, as I understand them, by referring to the institute of marriage. In many societies, marriage is a stabilizing institution. If marriage law were subject to constant revision, this would undermine social coherence. Many aspects of the concept marriage therefore belong to the form features of identity within a particular society.

However, due to changes in the content features of certain identity constituting concepts, form features may eventually change. In the case of

marriage for instance, the fact that gay marriages are now legal in the Netherlands, is due to some extent to changing (secular) attitudes towards marriage. While previously people conceived of marriage as something with a practical value, a coalition between two parties that would produce offspring, now the understanding of marriage has shifted increasingly to the expression of a unique romantic connection between two persons: a symbol of love rather than of social custom. Since gay couples cannot produce children on their own, but can form loving attachments, the existence of gay marriage fits the modern understanding of marriage more than the older understanding of marriage. In this case, the form features have changed due to alterations in the content features.

The legitimacy of form features of identity derives from their enabling function in society. According to Laden, the more public an identity is, the more its articulation is constrained by form features (see Laden: 2002, 110). The identity of citizen is, for instance, highly constrained by form features, as Laden points out himself. To act out his role as citizen, that is to act in political contexts, an individual needs to take account of the rights and duties that are typically associated with such a role, because he interacts with, and offers reasons for specific claims on other citizens. The form features capture those aspects of his identity that he is obliged to acknowledge if he is to be recognized in his identity as citizen by other individuals. This identity offers a basis on which mutual claims between citizens can be justified, as will be explained more thoroughly further down and because the identity of citizen is shared throughout society, there is little room for individual interpretation of this identity. An individual acting in her capacity as a mother is primarily acting within a private sphere: the claims she makes on other people concern primarily her family. The need to justify the claims she makes is limited solely to that family, which increases her freedom to deliberately construct her identity within her family.

I take these form features to also exist in a moral sense. This understanding of form features is compatible with Laden's approach, although he does not explicitly mention the moral aspect. We attach certain rights and obligations to specific identities, for instance to government officials or to legal partners. For instance, we expect government officials to act for the sake of the common good and we expect legal partners to take care of each other. If individuals do not comply with these moral rights and obligations, their identity may not immediately alter in a legal or social sense, but it may be questioned. A

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government official who allows herself to be corrupted by gifts from interested third parties or a wife who mistreats her husband, may be able to retain their social identities, but they have acted contrary to the rights and obligations we usually attach to these identities.

I furthermore propose to extend the concept of form and content features to scientific practice, something that Laden does not do. Why this is important and how it should be done will be explained in the next section. Science is not an identity, but it is a social and cultural practice that is constitutive for the identity of individuals within modern, western society, and in many other societies. How this is related to autonomy is discussed below.

### 3.3.3.3. Reality constraint

Individuals who appear not to be in tune with fundamental facts about reality are usually considered to be less responsible because they suffer from an unsound mind. They appear to be incapable of adequately assessing their own motives and preferences and also not apt to judge the basic features of the world around them. Such people are usually not trusted to behave autonomously as their judgments, which might lead them to make decisions against their own interests, are questionable in general (see Faden & Beauchamp: 1986, 253). Narratives that constitute people's identity need therefore to comply with reality in some important respects. However, as stated before, not all aspects of beliefs about reality are equally solid and indisputable. It is not always clear which description of reality is most accurate. Different descriptions may sometimes appear equally valid, and it may not always be possible to discern which description is closest to the truth.

It is assumed in this research that a basic agreement on fundamental aspects of reality usually exists within a specific community, society and for some features of reality even on a global scale. Without such agreement it would be very hard for us to live with each other. To quote Williams (2004): "...co-operative decision making requires a shared reality because it depends upon collective use of language and conceptual categories" (p. 96).<sup>5</sup> We need a shared sense of

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<sup>5</sup> What this shared reality encompasses precisely depends on the character of the shared decision making. If the only contact between individuals is mutual trade, than an understanding on the nature of exchange may be sufficient. If individuals share a full fledged society, the agreed shared reality will need to be more elaborate and comprise a wide array of concepts.

reality to be able to understand each other. Or, as Schechtman (1996) states: “Fundamental agreement on the most basic features of reality is required for the kinds of interactions that take place between persons to be possible”(p.119). Moreover, regardless of whether the content of these agreements is accurate or not, they undeniably shape our world. Understanding oneself and being able to assess one’s interests and to act accordingly therefore requires at least some compliance with the agreed shared reality.

This kind of agreement is not constantly open to debate and does not require continuous affirmation. It is embedded in the social structure of our society. It consists of both common beliefs, i.e. the earth is round, as well as truth-seeking practices such as science. Science is an institutionalized way of producing knowledge. Some basic features of the practice of science can be understood as widely accepted methods for delivering accurate descriptions of reality. These basic features are not constantly open to debate or revision. They serve as discriminative principles when establishing our shared reality.

Adherence to a shared, agreed reality on crucial aspects is equally indispensable for constructing narratives as adherence to cultural narratives. The difference between cultural narratives and a shared, agreed reality is that the features of the shared agreed reality are determined by truth seeking practices such as scientific inquiry, whereas cultural narratives, and the concepts and conceptual relationships they contain, are products of social, historical and cultural developments. Such concepts may be solid and closed for revision, but that is not because they have been proven, it is because they are such a pivotal element of a society that they have become indispensable. The concept of citizen for instance, is indispensable for modern, democratic nation states.

In contrast, the durability of scientific facts, concepts and causal relationships depends on their being proven within a framework of scientific practice. Proof is defined with reference to several criteria, such as reproducibility, coherence with other widely accepted hypotheses, simplicity, explanatory power and support by evidence and a stringent, conservative burden of proof (cf. Wandall: 2004). These criteria can be termed epistemic norms, they serve as discriminating principles, used to establish the content of our shared reality. In this respect their worth is similar to that of cultural concepts: they have become indispensable elements of our society.

The same distinction can be maintained here, as with the Articulation constraint: namely a distinction between form and content features. With regard

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to science, which is also a social institution, the form features consist of the methodological constraints on the production of knowledge, whereas the content features consist of the content of that knowledge. Due to changing content features of science, form features may also possibly change, but only over time. Sometimes the evolving content features of science may undermine one of these epistemic values, but only in a specific context. Quantum mechanics theory appears to be irreconcilable with the theory of general relativity, both theories can therefore be considered to be non-compliant with other established theories. However, since both theories adhere to all other epistemic values, this one aberration is temporarily accepted, but only in this specific case, and with the expectation that this problem will be resolved in the near future (see Hawking: 1996).

The content features of science consist of propositions, and the conditions under which these propositions are assumed to be true. A specific scientific claim about a phenomena may for instance be rejected on the grounds that the experimental evidence to support this claim is inadequate. This is the case, for instance, in the dispute about the alleged negative health effects of electromagnetic radiation as used in mobile phone technology (MPT). Promoters of MPT believe it is safe. Opponents claim that the experiments conducted so far have not sufficiently taken into account the effects of radiation in the long term, but instead have been confined to short term effects, thus the claim that electromagnetic radiation does not produce negative health effects is therefore unfounded, the opponents state. Neither of these claims can be dismissed for failing to comply with the form features of science, neither the claim that electromagnetic radiation produces negative health effects, nor the claim that it is safe, can be entirely dismissed on the basis of the available scientific evidence. In this case, science has so far been unable to resolve the dispute. To proceed from this deadlock, other non-epistemological values need to be invoked. This particular case is discussed in chapter 6.

### 3.3.4. Narrative autonomy

The narratives we construct that underlie our sense of identity enable us to be autonomous individuals. The personal storyline that connects seemingly unrelated events gives us a sense of direction and where to head next. Narratives enable us to frame situations and problems in such a way that they make sense

to us and allow us to reflect on them. This is where the concept of narrative autonomy is extrapolated from Schechtman's and Laden's ideas on identity. This concept is conceptualised explicitly to extend the concept of narrative identity as the basis for autonomy. Schechtman states that identity should be able to fulfill some vital elements of individual personhood, but she does not explicitly mention autonomy.

My account also differs from Susan Williams's conception of narrative autonomy. Both accounts are similar in that they explicitly recognize the importance of relationships for the exercise of autonomy and that self understanding is basically narrative in structure. However, the accounts differ in that they identify different aspects of being a person as the locus for autonomy. My account is foremost an adaptation of what Williams terms the 'rational reflection' model (see Williams: 2004, 155) of which Frankfurt and Dworkin are famous exponents. This model is characterized by a strong focus on reflection, choice and agency. My concept of narrative autonomy adapts this model in such a way that it can incorporate the relational, emotional and social aspects of autonomous behavior.

Williams' account amounts to a more radical departure from the so-called rational reflection model of autonomy in which choice is central to autonomy. For Williams, the locus of autonomy is the construction of personal narratives.

"The primary experience and exercise of autonomy takes place not when we choose, but when we tell our stories (...). Our identities and our lives are conceived in this model in narrative terms and the meaning of autonomy is that one's identity and life are not "the object or medium of someone else's speech, [but rather] the subject of one's own." (p.149)

My own claim is that autonomy does not reside in the construction of narratives, but rather that the narratives we construct for ourselves are what enable us to be autonomous individuals. Identity and autonomy should be understood as two distinct concepts that interact. Identity is a prerequisite for autonomy, while control over one's identity requires some degree of autonomy. Although the construction of a personal narrative is undeniably an essential element of leading an autonomous life, it is not what exemplifies personal freedom.

In my view, to conflate the formation of identity and the exercise of autonomy obscures the relationship between identity and autonomy. Autonomy is the ability to make and enact choices according to your moral framework: in order to be an autonomous individual, one must have a reasonably



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comprehensive understanding of oneself. Control over this understanding is not autonomy. Autonomy is, in my view, more about choices and following those choices than about the self determined construction of identity. I think we should try to preserve the model of autonomy in which choice and reflection are paramount because it offers useful concepts for considering the autonomy of the individual in a political context, and more specifically, for considering the *limits* to individual autonomy within such a context. In the context of my research, such issues are highly important.

Williams' focus on the construction of narratives as the locus for autonomy raises the question whether that leaves us with any means to criticize an individual's autonomous actions or deem them to be non-autonomous. Williams' focus on recounting one's story according to one's own best insights, does not allow for any distinction in the quality of those stories. Williams states that she would not consider a person autonomous who constructs narratives of herself solely in implicit ways, so it is possible for Williams that people do not live up to the requirements for autonomy (see Williams: 2004, 155). However, it seems that as long as the stories told are explicit in some sense, anything goes. This approach fails when respect for autonomy is considered in a political context where the autonomy of one individual may limit the autonomy of another individual.

Although I very much appreciate Williams' account, I think she unnecessarily conflates the concepts of identity and autonomy, and further fails to provide insights into how firstly, an individual can fail to be autonomous and secondly, how the autonomy of an individual may be constrained by either the autonomy of others or social values that we hold dear. My concept of narrative autonomy states that the only arguments and claims that should be recognized as autonomous are those that live up to the reality and the articulation constraint. These constraints are used to distinguish autonomous from non-autonomous arguments and claims, while incorporating the importance of social context. The constraints also embody respect for the autonomy of others, as they ensure that autonomous claims and arguments are meaningful to other individuals, and by ensuring that not all arguments can be taken as a ground for interference with personal freedom.

### 3.4. Implications for risk assessments

What bearing do these considerations about autonomy have on the issue of respect for autonomy with regard to technological developments and their accompanying risks? Three main recommendations can be proposed for decision procedures on the acceptability of risk as listed below and will be discussed further in this section.

- (1) Decision procedures on the acceptability of risk should be organized in the format of public and political debates.
- (2) The quality of the arguments should be determined by adherence to the articulation and the reality constraints.
- (3) The burden of proof should rest on the party who is most capable of providing that proof, given the identities of the different parties involved.

#### 3.4.1. Public and political debates

The first recommendation to structure decision procedures on risk in the format of public and political debates has also been discussed in chapter 2 (2.4.2). I argued there that the format of public and political debates is required to accommodate the collective character of decision procedures on the acceptability of technological risks. Public debate involves discussions about the representation and estimation of risk, whereas in the political debate, decisions relating to the actual management of the risk are discussed. The distinction between the public and the political debate has ramifications for the issue of identity. The distinction between public and political debates is based on Laden (see Laden, 2001, p.100 -107) although in a slightly amended form due to my focus on respect for autonomy. According to Laden, different aspects of identity are relevant in the two different debates. In public debates, particular individual identities can play a role. In political debates, a common political identity dominates.

In a debate on the acceptability of nanotechnology for instance, the public aspects of the debate may concern the following issues: What risks are involved in nanotechnology? Is there anything new about nanotechnology? What benefits can we expect from nanotechnology? In relation to these questions, people will

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invoke their particular identities. They will bring forth arguments based on their identities as mothers, as physicians, as manufacturers, as teachers etc.

Public debates offer a forum to exchange ideas and arguments that do not necessarily lead to political action, but which may turn out as reasons for political actions. Such political actions are not directly at stake in the public debate. Therefore, in the public debate, people do not solely act out of their political identity. Other aspects of their identity are also relevant. As such, this debate serves to deliberately construct particular identities (see Laden: 2001, 101), by exchanging arguments and points of view, individuals can refine their own perspectives on things and hence their own narrative identities. They will receive input from other individuals on the narratives that give meaning to their lives and this can help improve the consistency and articulation of such narratives. In principle, any perspective may be offered in the public debate. It is assumed here, following Mill (1859/1972), that it is extremely important that a great diversity of opinions is brought forward as this is assumed to aid the epistemic quality of such opinions.

The public debate serves as input for the political debate. Only those claims that can be recognized as legitimately autonomous should be allowed into the political decision making process. In my approach, claims in the public debate that can be recognized as legitimately autonomous are those that can be shown to reside in one's identity, personal narrative, and that are compatible, in some crucial aspects, with surrounding socio-cultural narratives including the scientifically framed narratives. As discussed above, this basically implies compliance with the form features of science, i.e. epistemic values, and compliance with the form features of identity.<sup>6</sup>

The debate becomes political in nature once the issue of how to deal with a risk is discussed. This question is political because it concerns activities that can affect people directly. These activities will have societal consequences. Typical questions include: What policies should we employ with regard to technological developments? Which risks are we willing to take? Who is responsible for these risks? In the political debate the various autonomous arguments from the public debate will be assessed on their political tenability. Participants are expected to bring forth public reasons, implying that they issue from their identity as citizen. Public reasons are those reasons that are shared between citizens in a society. As

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<sup>6</sup> Laden does not explicitly consider qualifying the input from the public debate into the political debate.

Laden states (2001, 116): "... a reasons will counts as a public reason if fellow citizens can be made to see that it is supported by the public identity that they can and do share." How this works out exactly will be explicated in the following section. After considering these arguments, a decision should be reached on the desirable course of action. The typical actor to make this decision would be the body of democratically elected representatives.

### 3.4.2. Constraints on arguments

As decisions regarding the acceptability of technological risk can have wide-ranging effects on other individuals, constraints should be placed on arguments that can be considered autonomous. Only those arguments that meet certain criteria for quality have to be respected by other individuals.

Each kind of debate involves different constraints. In the public debate, the relevant constraints consist basically of the articulation and the reality constraint. The articulation constraint requires that individuals present (the narrative of) their argument in a coherent form in a way that respects the form features of relevant (public) identities. The reality constraint requires that any representation of risk put forward is compatible with the form features of science.

In the political debate, the most relevant constraint is the articulation constraint, but not in its general form, but specifically as applying to the form features of citizenship. This implies that any argument put forward in this debate will be assessed with regard to the form features of citizenship. Arguments in this debate are assumed to have met the more general demands of both constraints in the public debate; otherwise they would not be allowed in the political debate.

#### 3.4.2.1. □ Constraints in the public debate

In the public debate, the articulation constraint and the reality constraint operate to distinguish autonomous from non-autonomous arguments. There are several characteristics of this process I would like to stress here. First of all, the constraints are supposed to act retrospectively. A wide array of arguments may be brought forward, after which they can be assessed on their merit.<sup>7</sup> Any

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<sup>7</sup> I do not consider the question of who should assess these arguments. I think this is an important question, but not one which is essential to the argument I am presenting here. My

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perspective of a specific risk is initially allowed, but only those perspectives that meet the reality and the articulation constraint have to be acknowledged as autonomously made claims by other participants.

Secondly, the public debate should be open to a wide array of competing conceptions of similar risks. This is to ensure that the diversity of perspectives from different actors is uncovered. The reality constraint distinguishes those representations of risk that are compatible with the form features of science, from those which are not, but within this constraint there is ample room for diversity.

Thirdly, aside from offering input to the political debate, the public debate also serves as a platform to deliberately construct identity constituting narratives. This deliberation should be such that identities are not enforced upon individuals. For the deliberate construction of identities to be acceptable, it needs to be open and in respect for each individual's perspective (see Laden: 2001, 6) However, in my view, the articulation constraint implies that there are some aspects of identity that may be enforced upon other people without their consent. Such aspects include, for instance, the form features of identity. An individual cannot deny having obligations towards her husband for instance. Once one takes on a specific socially defined identity, one has to accept both the rights and the obligations associated with this identity. This claim is not explicitly made by Laden, it is my own interpretation of how the form features of identity map unto the Articulation Constraint.

### 3.4.2.2. Constraints in the political debate

In the political debate, the articulation constraint is most relevant as it applies to the political identity of citizens. In political debate, a decision needs to be made with regard to the management of a technological risk that can ideally be justified to all participants by reference to the form features of citizenship; by requiring justification in this sense, the autonomy of each participant is respected. As argued before (section 3.2.1) such justification need not be conclusive in the sense that it can be reasonably expected to elicit consent from each participant. Rather, the justification derives from the appeal to shared reasons. According to Laden, shared identities give rise to shared reasons; by

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most important contribution is that the arguments should be assessed according to specific criteria, irrespective of which actor takes on the assessment.

acknowledging an argument as a reason with a certain appeal within a debate, we acknowledge the moral import of that shared identity (see Laden: 2001, ch.4).

The identity of citizen is such a shared identity that it can be expected to carry a certain moral weight to a large group of individuals who acknowledge the identity as their own (see Laden: 2001, ch. 5).<sup>8</sup> In political debates, the individual asks others to acknowledge her claim on the basis of their mutual identity as citizens (see Laden: 2002, ch.5). As citizens, individuals owe each other mutual respect as participants in the political debate. This mutual respect is the cornerstone of democratic decision procedures which enable people to create and maintain a society.

One's identity as a citizen of a specific society consists of an articulation of the kind of values we regard as constitutive for being a member of that society. The legitimacy of the form features of political identity and the accompanying reasons derive from their enabling function in democratic politics. The form features enable us to live as free individuals within a modern democratic society, and to engage in public debates about political issues (see Laden: 2001, 114). They enable us to make claims on each other as autonomous beings. These values are valuable for the instrumental reasons mentioned in this paragraph, but they also have intrinsic value.

In a modern, western society the following features may be considered fundamental, in my view, with regard to political debates on the acceptability of risks<sup>9</sup>.

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<sup>8</sup> This appeal to shared reasons is comparable to Rawls's appeal to shared reasons (see Rawls: 1996). However instead of relying on a particular conception of justice, Laden instead relies on the notion of identity in general, and in particular, the identity of citizen (see Laden: 2001, 117)

<sup>9</sup> This list is not necessarily exhaustive but I think these values are highly relevant in the context of political decision concerning technological risks. These values are partly taken over from Laden and inspired partly by Childress & Beauchamp's famous quartet of ethical principles for the medical context and adapted to a situation of decisions on the acceptability of technological risks. (see Beauchamp & Childress: 1994) Laden's (2001) set of constitutive values includes freedom, equality and overridingness. His quality of obligatoriness is not included as I do not consider this to be of paramount importance with regard to decision procedures on risk. Instead I have added non-maleficence and justice because I think that these are important values when it comes to issues related to technological risks. Here I follow Beauchamp & Childress who include these values for a context in which comparable issues arise as in the context of decisions on technological risks.

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- Political equality: the value of equality reflects the respect we think each individual deserves in principle because we are all human beings. To quote Shrader-Frechette (2002, 26): “This principle provides the basic justification for other important concepts of ethics and is a presupposition of all schemes involving justice, fairness, rights and autonomy.” This principle or value does not imply similar treatment in all cases, but rather that everyone ought to receive the same, or consistent, concern and respect in the political decision about how goods, treatment and opportunities are to be distributed (see Dworkin: 1977). As Buchanan (2004, 117) furthermore claims, equality is important instrumentally as a contribution to the quality of social epistemology: it demands that all possible perspectives are in principle allowed within the debate, and that all possible perspectives deserve to be weighed equally. This value helps us to arrive at solutions for political problems that do justice to the greatest variety of interests.
- Justice: this value reflects the idea that people ought to receive what they deserve. “A situation of justice is present whenever persons are due benefits or burdens because of their particular properties or circumstances, such as being productive or having been harmed by another person’s act” (see Childress & Beauchamp: 1994, 327). With regard to technological risk the value may more specifically be defined as: “... the morally proper apportionment of benefits and burdens – such as wealth, opportunity, education, toxic waste dumps, dirty air, and so on – among society’s members” (see Shrader-Frechette: 2002, 26). A lack of justice would lead to social anarchy and a culture of fear. An open society will not function without a foundation of justice and it would be an unfair society.
- Freedom: freedom from oppression is essential to well functioning western democracies; for reasonable political deliberation people should be free to accept or reject reasons offered to them, within reasonable limits. They should also be free to voice their concerns and hence offer reasons to other citizens (see Laden: 2002, 134). Freedom is furthermore important to ensure diversity within a society.

Aside from instrumental reasons, individual freedom is valuable in itself. It has traditionally been one of the main goals of modern western democracies: a goal shared by different political movements, such as liberalism and socialism alike.

- **Non-maleficence:** in principle, we try to avoid harming other people. People have a right to bodily integrity, implying that their bodily health deserves respect from other individuals. As Childress & Beauchamp define this value: “One ought not to inflict evil or harm” (see Childress & Beauchamp: 1994, 192) If we want to live together, it is important that we respect the integrity of each other’s bodies and minds. This value contributes to a democratic society because it creates the possibility to rely on each other, without fear of being hurt by the other person. As Giddens (1991) states: reliance on each other in a broad societal sense is indispensable for a stable society. Furthermore, people should not be hurt by other people.
- **Overridingness:** the form feature of overridingness indicates that in political deliberation, the dominant aspect of one’s identity should be that of citizen. “Part of what makes political deliberation reasonable is that participants offer one another reasons they regard in good faith as authoritative for others insofar as they are citizens (i.e., public reasons). Thus, one essential element of citizenship is that citizens, when engaged in political deliberation, restrict their arguments to what they take to be public reasons arguments. (...) Notice that this requirement is tantamount to the requirement that in political deliberation I allow my identity as citizen to override my nonpolitical identities” (see Laden: 2002, 115).

All arguments that are accepted within a political debate on risks should at least respect the above four values and their quality of overridingness since they constitute the form features of identity for citizens within a modern, western state. Compliance with these form features can be considered the articulation constraint of political debates. These values are taken to be of universal value. However, their specific interpretation may differ per cultural context, because of



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different historical, cultural and political developments, each community will apply these values differently.

The values of equality and justice are closely related. Usually, an equal distribution of social goods is considered a fair (just) distribution. As I apply these values in this context, equality refers most specifically to the requirement that each individual is granted equal consideration in the justification of the distribution of social goods. Justice refers most specifically to the actual distribution. Demanding that the interests of each individual are considered equally does not necessarily imply a specific distribution. Inequality in this context would imply that a specific perspective has been omitted from the consideration concerning the distribution of social goods. Injustice would imply that the different relevant perspectives have been balanced in a way that advantages some individuals over others without justification.

A remark needs to be made with regard to the value of freedom, which is closely related to respect for autonomy. Since the entire set of form features arose originally from a concern over respect for autonomy, it may seem that there is a circularity here, however, freedom as one of the five form features of citizenship is a requirement in a rather minimalist form. Freedom does not equal the elaborate sense of respect for narrative autonomy that underlies this research. It should be taken as a constraint on arguments offered in political debates in the sense that such arguments do not undermine basic freedoms of other participants such as the freedom of speech or freedom of association. As such, it should be considered a minimal form of protection of external freedom.

The last form feature of citizenship demands that all participants in political deliberation can transcend their particular perspective on the acceptability of a particular risk, and bring forth arguments that can be understood as public reasons. Moreover, they need to accept these public reasons as being of paramount importance in the decision procedure.

### 3.4.3. Burden of proof

When we consider respect for autonomy with regard to technological risks, the issue of the burden of proof is of pivotal importance. Usually the burden of proof is on the party who puts forward a claim. The third recommendation that follows from respect for narrative autonomy is that the burden of proof should rest with the party most capable of providing that proof.

To guarantee the quality of representations of risk, participants in decision procedures on risk need to show that their representation of risk is scientifically credible. As explained before in chapter two, such evidence need not amount to conclusive proof about a claim as this would run counter to respect for internal autonomy. A reasonable indication of a risk suffices as a claim within public debates. However, the representation of a risk needs to comply with the form features of scientific practice. In some cases, additional scientific evidence will be required to meet this demand. Not all participants to decision procedures about risks have equal access to the resources to provide such proof.

The social identity of the individual determines to a large extent her capabilities. Individuals with degrees in engineering have distinct capabilities different from individuals with medical degrees. The professional role an individual takes on will lead her to develop specific skills and provide her with experience in a specific field. In a narrative account of autonomy, the identity of individuals is of pivotal importance. If we take the issue of identity into account in allocating the burden of proof, then the issue of the capabilities of each actor becomes relevant (section 3.3.1). In relation to technological risks an indispensable capability with regard to autonomy is the capability to provide scientifically supported evidence of risk.

As argued before (section 3.3.2), if labour specialisation is to serve autonomy, the divergent capabilities of specialists should be in the service of those who lack specific capabilities. When it comes to the issue of providing scientific evidence for a technological risk, the party who is most capable of providing this evidence should be appointed the burden of proof, which includes carrying the financial burdens. Considering this aspect of identity, it is reasonable to require individuals to act according to their skills and capacities. We should not expect a philosopher to produce scientifically supported evidence for the risks associated with, for instance, nano technologically engineered sunscreen. Respecting autonomy does not only imply that individuals be allowed the freedom to do as they deem best, it also implies that the limits of the capabilities of an individual are respected. This argument will be elucidated in the case-studies.

The burden of proof does not imply control over the criteria according to which proof is defined. In this context, the burden of proof implies that parties should provide evidence according to criteria of harm that are determined in deliberation with other parties. These criteria have to meet the reality constraint

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and the arguments in favour of these criteria have to meet the articulation constraint.

### 3.5. From theory to application

The concept of narrative autonomy builds on useful insights of the concepts of autonomy as proposed by Mill, Kant and feminist authors. The concept of narrative autonomy and the recommendations that can be derived from it have some distinct advantages over the other three approaches. Whether these recommendations are indeed applicable to actual debates on the acceptability of technological risks will be discussed in three distinct case-studies. Firstly, the reference to a shared reality captured by the reality constraint allows to define the range of representations of risk that should be respected as autonomously made representations of risk. This approach assumes a shared understanding of what is required of useful production of knowledge. This shared understanding is embodied in the epistemic norms used to assess diverging representations of risk and to justify a possible basis for political action. In this way the Millian demand for justification of interference with autonomy is maintained, without the appeal to an assumed to be neutral concept of harm. Reference to the Reality Constraint allows for perspectives that follow from particular conceptions of the good life, as long as they are compatible with epistemic values. The usefulness of this approach will be illustrated in the next chapter in which we analyse the trade-conflict over genetically modified organisms between the US and Europe.

Secondly, the use of constraints, the application of which derives from the context, avoids the extreme relativism of the feminists while also steering clear of the empty formalism of Kant. The importance of context for moral deliberation is firmly incorporated within these constraints, while they still leave room to distinguish between autonomous and non-autonomously made arguments. The benefit of this approach will be illustrated in chapter 5, in the case-study of the debate on vaccination of children.

Thirdly, the reliance on the concept of identity for the formulation of shared values offers a basis for the justification of political decisions which avoids the problems of conclusive justification in which the consent of each participant is required. Such shared social values can also be said to be based on conclusive justification, but in a way that is more solid than individual consent. The basis on which a society rests is captured by the concept of identity of a citizen and all

members are assumed to subscribe to that basis or offer strong reasons to alter this basis. In cases of conflict, it should be clear that the four basic values take precedence over any other values, because of their quality of overridingness. They need not be argued for each and every time, and if they are contested, it is clear where the burden of proof lies. As such, shared political values embody a perspective of the good life, but one that can be expected to elicit consent from all members within a society. The benefits of this approach will be illustrated in chapter 6, in which I elaborate on a case-study on the debate about the alleged health effects of mobile phone technology.

Fourthly, assigning the burden of proof according to capacity explicitly acknowledges the importance of (social) identity for autonomy. This is an omission in the Millian approach to autonomy, which may lead to undesirable consequences in relation to respect for autonomy. The benefit of this recommendation is illustrated specifically in chapters 4 & 5. Lastly, all these recommendations as they have been applied in the case-studies, will be evaluated in chapter 7.



## 4 Criteria for evidence of risk in international trade regimes<sup>1</sup>

### 4.1. A trade-conflict

A recent trade conflict between the European Union (EU) and the United States of America (USA), together with some other nation states, on the acceptability of genetically modified organisms (GMOs) demonstrates contrasting approaches to dealing with autonomy. One of these approaches can be traced back to a Millian concept of autonomy, whereas the other exhibits a concern for identity as a central element of autonomy. In this chapter I deal with the question: which of these approaches is most adequate considering the value of respect for autonomy?

The EU until recently upheld a *de facto* moratorium on the import and the production of genetically modified organisms. This moratorium was justified making reference to the precautionary principle (PP) in relation with the unknown effects of GMOs on health and the environment (see Murphy 2004). The USA, Canada and Argentina reacted by complaining to the World Trade Organisation (WTO) that the EU had erected illegitimate trade barriers to their products (see Bridges: 2003; Wong: 2003).

The EU made a slight concession by allowing GMOs within its borders from June 2003 on the condition that these products were clearly labelled. In February 2006, the Dispute Settlement Body of the WTO condemned the moratorium, but also stated that it considered the moratorium expired and would not take further actions against the EU (see Baumüller *et al.*: 2006).

This trade-conflict exemplifies the clash between different appraisals of what counts as legitimate concerns in the acceptability of risks (see Isaac & Kerr: 2003; Jasanoff *et al.*: 2004). These different appraisals are embodied in the policies of two international bodies governing trade in GMOs: the WTO and the United Nations (UN). The UN has issued an alternative to the WTO policies for dealing with trade in GMOs: the Cartagena Protocol on Biosafety (CPB).

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<sup>1</sup> This is an adapted version and extended of Asveld (2007)

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In principle, both the WTO and the UN as organizations hold self-determination as an ideal, but they develop different policies to serve this ideal. The WTO solely accepts considerations of a scientific nature when determining the nature and acceptability of a risk, whereas the UN-protocol also regards other concerns as valid. This difference can be linked to different concepts of autonomy.

It will be argued that the UN approach is ethically more tenable because it better guarantees respect for autonomy. This is because firstly, the UN approach accommodates internal autonomy better. Secondly, the strong focus in the WTO approach on external autonomy leads to misconceived policies with regard to risk. The UN approach offers a balanced approach towards respect for both internal and external autonomy of nation states, and consequently for individuals. This approach should therefore be preferred in this context.

In this chapter it is argued that the autonomy of individuals is essentially linked to the autonomy of nation states, therefore the autonomy of nation states should be cherished. Additionally, in this context similar considerations are relevant for the autonomy of individuals as for the autonomy of nation states. Therefore this case study can be considered relevant to the general purpose of this dissertation. I will first explore the relation between individual and national autonomy. This will be followed by an analysis of the policies of the WTO and the UN in relation to individual and national autonomy.

### 4.2. Autonomy of nation states<sup>2</sup>

So far the focus has been on the autonomy of individuals, however, in the context of the WTO and the UN, conflicts mainly take place between nation states. In this chapter, nation states will be the focus of the analysis. The remarks on autonomy made in the previous chapter are also relevant for the autonomy of nation states.

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<sup>2</sup> I understand nation states to be political entities with a specific national identity. This identity is however not necessarily limited to one ethnic group. Several ethnic groups may be part of the same nation state. A state may be considered a nation state when it has a distinct identity, exemplified by such qualities as a dominant language, historical consolidation and prominent cultural heritage.

#### 4.2.1. The moral relevance of nation states

Why does the internal and external autonomy of individual nation states deserve respect at all? It is because nation states can be seen as an essential prerequisite for the autonomy of individuals, for two reasons. One, nation states offer a unique forum for, groups of, individuals to achieve objectives that are beyond the reach of individuals acting in isolation (see Wendt: 2004, 299). Two, the nation state provides a framework of political identity which is an enabling condition for the political autonomy of the individual (see Laden: 2002; Schnapper: 2002).

With regard to the first reason: the nation state and similar entities can provide social security, public health policies, adequate infrastructures and domestic security in a way that respects the relevant cultural, historical, economic and social characteristics within a specific region.<sup>3</sup> Moreover, and especially relevant in this context is the task a nation state has in regulating and monitoring health and safety issues within its borders.

The nation state is not the most suitable actor for all policy issues, but it is for some that are especially sensitive to cultural, historical or geographical qualities. They include, for instance, public health policies, drugs legislation or food directives. The Netherlands has, for example, a unique approach towards the issue of euthanasia and drugs legislation within the EU. This particular stance can be linked to a historical culture of tolerance and openness to debate. Similarly, France has a culinary tradition in which 'industrial' foods are regarded with hostility (see Guillou: 2001). This hostility was exemplified by the widespread support for José Bové's dismantling of a McDonalds-franchise in France in 1999 as a protest against intensive agriculture. This cultural characteristic will make the French, overall, more suspicious towards GMOs than for instance many North American citizens.

Some policy areas that used to be confined to national legislation are more effectively dealt with by a supranational body. Authority over such issues is increasingly being transferred to bodies such as the EU, for instance the handling of environmental problems that transgress national borders or dealing with international security. I will not defend a thorough division between issues

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<sup>3</sup> These kinds of issues may also be taken up by smaller governments, such as regional states. Most of the considerations put forward are also relevant for such actors. However, since the WTO and the UN mostly involve nation states, the focus in this chapter is on nation states.



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that are better dealt with at a supranational level and those that are better dealt with by national bodies here. However, the central claim remains that the handling of health and safety issues is best left to nation states.

With this remark I criticize the attempt made by the EU to concoct a unified approach towards the import of GMOs, as it foregoes the specific perspectives of the individual nation states. However, this approach is not altogether negative in terms of the autonomy of the individual member states. This approach appears to be a compromise between respecting the unique perspectives of all member states and simultaneously being effective in terms of international relations. Individual states can enlarge their international influences as member of the EU and hence enhance their autonomy, while at the same time diminishing their autonomy by adapting to a common strategy.

A similar consideration is relevant in the context of individuals. If they are able to make all decisions solely on a basis of their own perspectives, they would never need to compromise. However, within the structure of a state, individuals will need to make compromises, but in return they will receive benefits they would never be able to achieve on their own, such as large infrastructures and health institutions.

Dealing with issues related to the acceptability of risks cannot be left to the market, as markets are often imperfect and unable to deal with externalities. Not all consumers will be able to make informed decisions about GMOs simply because of a lack of resources, time, knowledge, etc., to process the information available. The use of some GMOs may furthermore have consequences for other individuals than the consumer who purchases genetically modified products. This is the case, for instance, when GMOs are used for agricultural production. A farmer using genetically modified seeds threatens the ecological integrity of a neighbouring farmer due to the risk of cross-pollination. An unregulated market will favour the autonomy of the consumer, without consideration of the autonomy of non-consumers. (I have discussed this point more elaborately in chapter 1, section 2.2).

The belief that an unbridled market economy will serve the interests of everyone, as the WTO proposes, furthermore assumes that all actors are equally well equipped to enter the market and use it to their advantage. In a global context, this is certainly not the case as some actors have considerably more resources than others at their disposal to begin.

Such inequalities between individuals may to some extent be countered through the agency of nation states. In the context of a nation state, weaker parties will receive some protection and guidance within the overarching structures of the states. The inequality between nation states will remain, but at least through the structure of their states, even if they are not very powerful states, disadvantaged individuals may hope to exert some influence on global developments that affect them.

Issues of national interest such as health and safety can furthermore not be left to parties representing specific interests, such as NGOs expressing environmental or religious moral convictions. Although these parties often offer valuable input into policy development, they lack the resources and the legitimacy to control markets or install and monitor safety regulations.

With regard to the second reason why nation states are prerequisites for the autonomy of the individual: the nation state offers a specific political framework enabling the individual to be politically autonomous. Each nation state has its own specific identity. As such, each nation state offers citizens a framework of reference for constructing aspects of their personal identity. Vice versa citizens make up the identity of a specific nation state. This is an ongoing interactive process. For most people, being part of a specific nation state has implications as to how they see themselves. The influence of nation states on individual identity may be diminishing because of the effects of globalisation such as increased interstate communication; nevertheless aspects of individual identity can be expected to remain linked to national identity (see Held: 1995, 124-127). As explained before, identity is of fundamental importance to autonomy.

National identity will provide some guidance in the process of political decision making. The nation state provides an organizational structure between social actors, and the definition of these actors and their mutual responsibilities (see Castells: 2004, 8-9). Its political structure will furthermore consist of a shared set of values. A shared set of values is indispensable in the process of political deliberation (see Laden: 2002). Even if citizens do not actively engage with or endorse the political structure of their state, they still depend on it, and are shaped by it (see Held: 1996, 295; Castells: 2004, 9) A nation state gives individuals a sense of meaning, if only on specific aspects of identity, which is inalienable for individuals if they are to be considered autonomous beings, especially considering the political aspects of autonomy. Neglecting state identity

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and thereby its autonomy can therefore undermine the autonomy of the individual.<sup>4</sup>

### 4.2.2. States as persons

The focus of this chapter is specifically on the autonomy of nation states, considered as an extension of the autonomy of the individual. Similar considerations as those put forward for individuals, are relevant for the autonomy of nation states. This is because nations are comparable on certain salient qualities to individuals when it comes to considering autonomy. I will not venture here into the discussion of whether nation states can be personified, or whether they merely resemble persons, my claim is solely that nations share at least some qualities of persons which are relevant when discussing state autonomy.

Firstly, nations can be considered to be intentional agents (see Wendt: 2004). Actions such as warfare, national government, international lobbying are instances of collective intentional agency. This collective intentionality is a result of the intentions of individual citizens. Simultaneously, as said above, the intentions of the individual citizen will vice versa be shaped by the character of collective intentions.

Secondly, nation states can be said to possess a certain kind of identity, just as individuals do. Nation states, by means of representing agencies, will assess options for policy with reference to their identity, in a way similar to that of individual persons. A nation state that prides itself on its tradition in ecologically sustainable farming may hesitate to introduce chemically intensive farming methods. Some nation states may be more able to assess the merits of new farming practices and effectively deal with these than others, as they may have extensive experience with technologically advanced applications in other fields. Such differences in capabilities to assess technological developments in no way undermine the autonomy of these nations, they solely hint at, valuable, differences in capacities and identity between nations.

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<sup>4</sup> I am aware that the actual formation of nation states may at the time have undermined the autonomy of individuals, as their specific identity at that time may have been denied for the sake of forging a unified state. However, here I am not considering the historical legitimacy of nation states. I am considering nation states as they are now, and the meaning they convey nowadays, irrespective of the harm their formation may have done in the past. I regard the past of nation states as part of their identity and also as part of the identity of their citizens.

As such, nation states can be said to behave as if they have subjective reactions (see Wendt: 2004, 313). States are said to be angry, humiliated, proud, aggressive: all terms we would usually use for persons, but which are very apt for describing the reactions of nation states. They are used to describe the dominant collective attitude prevalent within a nation. So again, the individual citizens are the bearers of the subjectivity of the states, and as a whole, they can be seen as behaving in the same manner as an individual.

It is understood here that some nations lack a coherent frame of reference or identity, due to a lack of internal consistency. In accordance with the internal autonomy of individuals, nations may be in such a state that their competency for internal autonomy begins to fail. A civil war is the most prominent of such conditions. If there is an obvious discrepancy between the interests of the general population and those advocated by the agency representing a nation state, that agency should not be considered as representing the identity of the nation state in question. However, most nations appear to be above the threshold for internal consistency due to a stable political situation in which basic human rights are respected.

### **4.2.3. Autonomy of nation states and risk**

As explained in chapter 2, divergent moral frameworks are very relevant in the assessment of risks (see Shrader-Frechette: 1991). This is true for nation states as much as it is for individual actors. Safety may, for one nation state, be paramount in comparison to nature conservation, while for another nation state nature conservation trumps safety concerns. Alternatively, the same value may be applied in extremely different ways. One nation state may interpret the value of safety as implying that new technologies should always be treated with carefully as they may bring about unexpected risks, whereas another nation state is more inclined to regard new technological developments as a likely contribution to increased safety, leading this nation state to give most technological developments the benefit of the doubt and/or subject it to less stringent safety tests.

A telling example of such differences in the assessment of risk is the different application of a similar procedure to identify possible harms attached to GMOs. The principle of substantial equivalence is widely used, but not consistently. The concept implies that if a particular crop is similar to another

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crop it is considered equally risky, irrespective of the method by which it was produced. So, a genetically modified tomato is considered to be equally safe as a non-genetically modified tomato since they are both tomatoes. However, to question which qualities of a crop determine its similarity to comparable crops, remains a manner of dispute that is currently ill-defined, leaving it up to the individual assessor to interpret the notion of similarity (see Tomlinson: 2000). Most crops are tested on their chemical characteristics, however, other qualities, such as genetic and biochemical composition can be relevant for determining the possibly toxicological effects of the crop (see Millstone: 1999). The form of the principle is clear and consistently applied, however the content of the principle differs per region. This controversial principle is generally less accepted as a basis for safety regulations with regard to GMOs in the EU than in the USA. The principle has been heavily criticised in the EU by both authorities as well as civil society groups (see Wong: 2003).

This difference in appraisal of technologically similar products shows that varying concepts of nature and technology give rise to different identifications of possible harms (see Isaac & Kerr: 2003). Ideas of what is natural or not, and how much we can trust new technology considerably determine the content of risk assessment. In the context of risks associated with food, the meaning of food within a specific cultural context adds to the differences in the appraisal of the risks associated with food (see Brom: 2004). The hesitation of the EU towards GMOs can be traced back to cultural characteristics of its members. France is for instance known for its aversion to novel foods, an aversion that is explained with reference to France's strong culinary traditions. Another nation state that hesitates when it comes to novel foods is the United Kingdom: the recent BSE food scandal has led the population to become very suspicious towards any potentially risky foods. Traditions and frightening experiences form elements of the national identity of nation states. Such elements should not be disregarded in advance as irrational or obstructive as they make up an important part of our conception of ourselves and of nation states as individual actors with individual rights and duties.

Moreover, such cultural identities enable nation states to identify and deal with moral issues. To disregard or deny such cultural identities is to undermine the sense of self of a nation state (or of a person), which is the basis for moral decision making. The cultural identity of nation states should be considered an

essential part of their autonomy, which among other things becomes clear in the context of the assessment of risks.

### **4.3. National autonomy, WTO and UN**

I will now discuss the policies of the WTO and the UN in relation to the internal and external autonomy of nation states.

#### **4.3.1. WTO and external autonomy**

The WTO is the international body that governs global trade. Its main objective is to guarantee free trade among its members. Almost all the nations in the world are members. The WTO exhibits a strong focus on the protection of external autonomy, i.e. freedom to act without interferences from other parties. The WTO can be said to actively serve the autonomy or freedom of its members by eradicating barriers to free trade as much as possible.

The WTO is a neo-liberal institute. It is based on the premises of liberal thought but with a specific interpretation that may not be shared by all liberal thinkers. Neo-liberalism can be seen as a radical interpretation of liberal ideology. Neo-liberalism manifests itself primarily as an economical doctrine, the aim of which is to reduce government intervention by individual states as much as possible and strives to harmonize regulations and trade regimes through multilateral organisations such as the WTO. In contrast, other forms of liberalism allow for more government intervention for the specific benefit of its citizens.

In contrast to the view on identity proposed in this research, neo-liberalism considers the individual to be a radically independent entity, or as Sandel (1984) terms this: the unencumbered self. This individual is assumed to be ultimately self reliant and to pursue her interests mainly through market transactions. This leads to a blind eye to inequalities between different groups in society, while other liberal doctrines may acknowledge these differences (see Held: 1996, 253-263). It is the neo-liberal character of this institute that makes the policies of the WTO problematic.

The WTO aims to achieve its objective by preventing the erection of illegal trade-barriers by its members. Under the policies of the WTO a nation state needs to provide justification for taking protective measures against the import of a particular product. Acceptable grounds for such measures are threats the

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product poses to health or the environment. Such threats need to be supported by scientific evidence. This is to prevent nations shielding their internal markets from external competitors with motivations that go against the free-market doctrine. This doctrine prescribes that markets will function optimally if they are open and competition flourishes. It is assumed that everybody will benefit from an optimally functioning market.

Individual nations may wish to reap the fruits of this free market system, without carrying the burdens, by exporting their own products, but refraining from opening up their internal market, thereby shielding their domestic markets from external competition. To prevent nations employing this tactic, the WTO is very strict in assessing the reasons nations put forward to justify the erection of trade barriers: these reasons need to be scientifically well substantiated (see Isaac & Kerr: 2003).

If a member of the WTO suspects that another member is unwarrantedly preventing a certain product from entering its borders, it may appeal to the Appellate Body of the WTO. This Committee will then look into the dispute and consider the tenability of the reasons brought forward to legitimize protective measures. These reasons need to be supported both in quantity and quality by a substantial amount of scientific evidence, otherwise the protective measures taken may be considered arbitrary discrimination (see Isaac & Kerr: 2003; Jasanoff *et al.*: 2004).

This approach excludes social and cultural concerns as valid reasons for taking protective measures. Such concerns may be labelled as concepts of the good life as they often emerge from moral frameworks that are specific to particular nation states. In liberal politics, interference with external autonomy is only legitimized if it can be justified, either through consent by the party whose freedom is interfered with, or out of protection, if the act constitutes a harm (see Gaus: 1996). Conceptions of the good life are not permissible as grounds for interference with the activities of others. Although some exceptions to this rule are allowed, the general spirit of the policies of WTO policies firmly encompasses the embracing of science as the only legitimizing discourse for interfering with the activities of individual parties.

Justification is required for interfering with another's activities, i.e. halting the import of a given product, that does not rely on concerns that can be labelled concepts of the good life. Instead evidence produced in relation to a specific risk should be 'conclusive', implying that no uncertainty remains as to the existence

of the risk at stake. This requirement is known as the requirement for 'sound science' (see Isaac & Kerr: 2003; Jasanoff *et al.*: 2004).

### 4.3.2. UN and internal autonomy

The UN approach can be said to explicitly respect the internal autonomy of individual nation states with regard to decisions of national interests, such as the import of GMOs. This respect is exemplified in the CPB, which will be explained below. This approach explicitly takes into account the diverging capabilities and moral frameworks of different nation states. As such it can be said that the UN explicitly respects internal autonomy, i.e. the fact that individual actors have different resources to make autonomous decisions. The specific cultural framework of a nation and its capabilities in terms of scientific institutions and economic development determine its capacity to assess technological developments and hence to make up its internal autonomy, for more discussion on internal autonomy see section 3.3.1. However, as will be discussed below, in relation to other issues of national interest it might be stated that the UN does not hold the internal autonomy of individual nation states to be of paramount importance.

#### 4.3.2.1. □ Cartagena Protocol on Biosafety

The CPB forms part of the Convention on Biological Diversity which aims to protect biological diversity. The protocol itself entered into force in September 2003, when it was ratified by the fiftieth nation state. The protocol differs fundamentally from WTO policies. This difference is most prominent in the central importance of the precautionary principle (PP) in the CPB. This principle clashes with the strict requirements for proof of risk set by the WTO. In the face of uncertainty, parties to the CPB are still legitimized in taking protective measures, such as halting the import of certain products, which would be considered an illegal trade barrier under WTO-policy. For the WTO, trade-barriers are only legitimate when the risk is scientifically unquestionable.

In the case of GMOs this implies that nation states may, according to the CPB, refuse the import of these products as long as they have a reasonable indication of the harmfulness of GMOs. Under WTO policies this would not suffice. Therefore the EU moratorium, which is a measure under the PP, was challenged under WTO regulation.



## Respect for Autonomy and Technological Risks

In the international arena usually any clashes between the CPB and WTO policies are avoided by a clause that is part of all UN protocols that states that the UN protocols are enforceable only as long as they do not contrast with WTO policies. In practice, WTO policies always take precedence over other multilateral agreements.

### **4.3.2.2. International decrees**

In other respects, the UN does not always hold the internal autonomy of a nation state to be of paramount importance. The UN regularly issues decrees concerning the national politics of specific nation states. Through these resolutions, the UN holds these nation states accountable according to a universalized moral system, such as the universal declaration of human rights. According to UN policies, nation states cannot claim to be justified in defecting this system by reference to their own particular moral framework or identity, although they may sometimes try this.

In this respect, the autonomy or sovereignty of the nation states is subordinated to a system of universal values that is deemed legitimate irrespective of the particular frames of reference or capabilities of individual nation states. However, even in this context, the UN often respects the individual perspective of a particular nation state.

The debate about the acceptability of risks differs from the above mentioned context of human rights in an important respect. The assessment of risks is not context independent similar to universal values, as explained above. The different moral frameworks constituted by the different identities and the capabilities of particular nation states are extremely relevant when assessing the acceptability of such risks. Therefore, in this area there is no ground for the UN to develop a policy that invokes universally applicable norms.

## **4.4. Evaluating the two approaches**

### **4.4.1. WTO: sound science and internal and external autonomy**

In the WTO approach, protective measures against risk are considered legitimate only if they are based on scientific risk assessment. This approach reflects a view on risk assessment as providing a universal rationality. It assumes that there is a

common assessment of risk available to every nation state; an objective language in which every nation state should be able to express its concerns.

This requirement for sound science might be seen as a means to assure that representations of risk are recognizable across different cultures and different regions. In the context of international trade this can be a very convenient quality. However, this stress on sound science is untenable with regard to autonomy for two reasons.

One, it does not do justice to the inherent subjectivity of risk assessments. As stated above, diverging moral frameworks lead to diverging subjective interpretations of risks. If there is no such thing as objective risk assessment available with regard to biotechnology, then the demand for conclusive evidence is impossible to meet. Conclusive evidence is only available within one specific framework of reference. The WTO approach leads to the singling out of one specific framework of reference as the conventional frame of reference. It thereby sets demands on the content of risk assessments. Only risk assessments that are compatible with a specific interpretation of what constitutes a risk are acceptable in the demand for conclusive evidence. Dominant concerns of a social, cultural or economic nature are very likely hidden in such a conventional way of performing a risk assessment, but are not recognized as such. This creates an unfair situation as parties who hold a different interpretation are denied the possibility to act in accordance with this. This is what is happening with the EU in its battle with the USA and its allies. The EU had its specific reasons for the moratorium, stemming from cultural concerns about novel foods. Such concerns deserve respect for reasons mentioned above. By its focus on scientific arguments, the WTO creates a bias towards one particular perspective (cf. Brom: 2004, 429)

Two and related to the first point, this approach disregards the fact that different nation states have different capacities for providing proof of risk. Industrialized nation states and multinational companies have a vast array of scientific and technological devices at their disposal, combined with the required knowledge. This is something most developing nation states lack. Developing nations do not have the resources to extensively test GMOs on their toxicological qualities. This does not imply that developing nation states do not have the resources to make autonomous decisions with regard to the acceptability of GMOs. They may have different ways of reflecting on the adverse effects of certain technologies.

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Both concerns relate to the issue of identity. Each nation state has a specific cultural history accompanied by specific capabilities. These are both aspects of the identity of individual nation states. As stated before, identity is fundamental to autonomy, as this provides the individual actor with a frame of reference that can be used to assess the actor's preferences. Identity is disregarded under the WTO approach.

### 4.4.2. Precautionary principle and autonomy

The UN approach offers more room for specific views on what constitutes a risk in deciding on the acceptability of GMOs. Under the CPB nation states can take recourse to the PP in the face of uncertainty. This option does require justification: it is not legitimate under all circumstances. In accordance with the WTO policies, the CPB requires a nation state to provide reasonable support for such measures, i.e. fear of risk needs to be based on scientific risk assessment. This implies that it has to be produced in compliance with the basic scientific epistemic values, i.e. the form features of science. However, such a risk assessment does not have to be conclusive. Risk assessments that represent a risk according to the particular social, moral and economic framework of a specific country are also considered legitimate, even if other parties do not subscribe to that specific representation.

Additionally, the risk assessment required to justify restrictions on the import of GMOs should be conducted in the nation state of import (see Gupta: 2000). This assures that considerations relevant to this particular nation state are taken into account. The criteria that determine what is regarded as a risk are constituted by the particular views of nation states. These criteria then be used to determine whether protective measures are justified. Even if nation states lack the rigorous testing facilities of industrialized nations and large biotechnology companies, they can still be expected to provide scientifically acceptable risk assessments using lesser facilities. They should however not be expected to provide risk assessments that are comparable to those produced by industrialised nations and large biotechnology companies. If necessary, the burden to provide specific required evidence should be put on those parties who have the resources to do this, i.e. on industrialized nations and large biotechnology companies, but in a manner that respects the diverging perspectives of the relevant actors. (I will come back to this point in section 4.5.2)

## Criteria for evidence of risk in international trade regimes

As said above, risk perceptions generally arise out of cultural, social or moral outlooks which may be very specific for a nation state. The criteria for proof of risk are defined by individual nation states in the UN approach: thus nation states are allowed to make their own assessments of risk, according to their moral framework and their capabilities, as long as these risk assessments comply with basic scientific rationality. This means that possibly salient aspects of risk according to the particular frameworks of individual nation states are not excluded beforehand. This approach accommodates the qualities of internal autonomy because it allows for the representations of risk that are specific to some actors as legitimate reasons to interfere with the freedom of others.

This accommodation of internal autonomy also has consequences for external autonomy, because the range of legitimate descriptions of risk is broadened, a shift occurs in the interplay between the external autonomy of the divergent actors. There is a wider range of legitimate reasons to protect oneself against the actions of others, i.e. against unwanted imposition from other actors. This strengthens the external autonomy of those parties seeking to protect themselves against the actions of others at the cost of the external autonomy of those parties seeking to push through some technological development.

The shift in balance between the external autonomy of various actors implies a shift in power balance. In this case, as in many other cases, the parties with the resources to develop new technologies are more powerful than the parties seeking to protect themselves against the perceived risks associated with a technology. Broadening the scope of legitimate reasons to interfere with external autonomy lends more power to otherwise weak parties, in this case to developing nations.<sup>5</sup>

The UN approach does not entirely shift the balance of power. The external autonomy of parties developing biotechnology is also respected but not in the same measure under WTO policies. Parties seeking to halt the import of GMOs still need to provide a risk assessment that does not contradict scientific rationality (see Gupta: 2000). This implies that the own standards of nation states are not the only ones that apply. The content of the arguments is left to the nation states themselves. However, the arguments put forward to justify protective measures should still live up to universally acknowledged standards set by scientific rationality. In this way, the freedom of parties to trade cannot be

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<sup>5</sup> The EU should not be seen as a weak party, but solely as a party that is not an industrious producer of biotechnology.

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interfered with just for any reason; the reasons need to accord with basic scientific norms.

In contrast to the WTO, with the UN, there is no time restriction as to how long a nation state can install protective measures. The CPB thereby allows nation states more flexibility in the face of scientific uncertainty (see Gupta: 2000, 2004). A nation state cannot be forced to abandon its protective measures solely because time has run out and the scientific justification has not come through.

In the WTO approach, if there is no conclusive scientific evidence available, a party may temporarily take recourse to precautionary measures (see Jasanoff *et al.*: 2004, 27). In the face of uncertainty, such measures may be used to gain more scientific information about the product under scrutiny. Such measures should, however, not cause undue delay, in other words, they cannot be applied for an indefinite period of time and preferably, only for a very short period. If the uncertainty continues, the precautionary measures will have to be abandoned due to a lack of conclusive scientific evidence, forcing a nation state to open its borders to the import of a GMO.

The CPB leaves more room for concerns about risks that are not necessarily substantiated by an extensive body of scientific literature. Uncertainty can be employed by individual nation states to take protective measures. This approach offers a procedural, rather than a substantive assessment of risks. A procedural approach implies that the content of a risk assessment is determined by the perspectives of the relevant actors, with the general demand that the risk assessment needs to respect basic scientific norms. In contrast, in a substantive assessment of risk the underlying assumptions defining the content of the assessment are determined by one dominant actor, such as the WTO, or any other regulatory institution. As Shrader-Frechette (1991a) has stated, a procedural approach does justice to possibly diverging interpretations of risks without necessarily falling into the trap of complete relativism.

### 4.5. Relation to narrative autonomy

#### 4.5.1. Articulation and reality constraint

This case shows how acknowledging the importance of identity for autonomy can influence decision procedures regarding the acceptability of risk. For

simplicity's sake I have not explicitly considered the relation of this case to narrative autonomy, I will do this below. Narrative autonomy requires that any arguments put forward are only recognized as autonomously made arguments if they respect the articulation and reality constraint<sup>6</sup>. Both constraints do not function explicitly in this case but the demands of each institution with regard to the quality of the arguments in decision procedures on risk can be interpreted as expressions of both constraints.

With regard to the articulation and the reality constraint the UN approach exhibits respect for both internal as external autonomy, whereas the WTO approach is mainly concerned with external autonomy. The most relevant difference between these two institutions exists with regard to the reality constraint. The WTO upholds a very strict, universalistic version of the reality constraint in contrast to the more context sensitive, open version of the UN. The WTO requires evidence beyond doubt as a form feature of the scientific evidence provided on the existence of risk. Parties can only be acknowledged in their claim to the right to protect themselves if they provide such evidence.

The UN solely requires a reasonable indication. This reasonable indication has to be presented in a format that respects the other form features of scientific practice, such as accordance with accepted theories, and simplicity. These lesser requirements leave more room for divergence in the representation of risk. Most importantly the UN does not hold on to a conservative standard of proof. This standard implies that if the scientific evidence is inconclusive, a hypothesis regarding the existence of specific phenomena or causal relations is rejected. To stay on the safe side, a hypothesis is only accepted when there is a substantial amount of evidence to support it. This prevents the false acceptance of hypotheses. However, when dealing with risks, such conclusive scientific evidence is hard to obtain. Using this standard for providing for decision procedures on risk excludes many otherwise viable representations of risk from consideration in such decision procedures.

Considering the somewhat contingent character of risk assessment and the differences in cultural frameworks and capabilities of different nation states, maintaining a more permissive form of the reality constraint better accommodates respect for the internal autonomy of a person or a nation state than the strict approach of the WTO. Additionally, the UN can also be said to show respect for external autonomy. Actors cannot interfere with the freedom to

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<sup>6</sup> For a thorough discussion of these constraints, see chapter 3

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trade of other actors just for any reason, their perception of risk still has to respect the form features of scientific practice.

With regard to the articulation constraint, both the WTO and the UN can be said to take a universalistic stance. Each member state is subjected to the same universal norms. The arguments of individual actors that do not respect the respective form features are not accepted as reasons for political decision making in either political arena, in theory at least. In the political context of the WTO the form features of this international political identity may be defined as 'respect for the freedom to trade'. Any interference with the policies of member states, e.g. if they seek to protect themselves against the import of allegedly risky products, can be justified with reference to this shared value. By signing the WTO agreement, with its strong focus on free trade, all participants agreed to respect this value during the decision procedures made in this arena.<sup>7</sup>

In the political context of the UN the form features of international political identity are explicitly stated in the Universal Declaration of Human Rights. The UN actively condemns violations of these rights by governing agencies using international decrees, thereby subordinating respect for the sovereignty of individual nation states to these values.<sup>8</sup>

In this international context the importance of the form features of political identities is especially clear. Each nation will have its own customs and traditions when it comes to political decision making. However, when these actors enter the international arena, they are expected to live up to the form features of international decision making. The particular political identities of nation states are not discarded, they are solely subordinated to that of an actor in an international context.

In the multicultural context that global politics presents I think it is reasonable to define values that can, and should be, shared by all participants. This does not necessarily undermine the internal autonomy of nation states as it enhances their capabilities to operate effectively as political actors in a global context. If nation states did not subscribe to such universal values their agency would be severely limited as they would lack a common ground that can be used to justify claims made on other political actors in the global arena. Such universal values do not undermine external autonomy as the implication is that interferences with the sovereignty of a nation state can be justified in a way that

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<sup>7</sup> Many countries have often acted in contrast with this value in the WTO-arena.

<sup>8</sup> The actual enforcement of decrees often proves problematic for various reasons.

is acceptable to the nation state, hence in a way that is legitimized with respect for external autonomy in a liberal, Millian sense.

With respect to the articulation constraint, the effect of WTO policies on internal and external autonomy is ambiguous. As said above, the subscription to shared values itself does not undermine either internal or external autonomy of nation states. However, as I have argued in this chapter, the way these values are defined under WTO policies and the ensuing demands on nation states are problematic with regard to respect for internal autonomy because the divergent capabilities and cultural frameworks of nation states are not taken into account.

In imposing some constraints on the arguments put forward by individual actors, the UN shows respects for both internal and external autonomy. Actors cannot interfere with the freedom to trade of other actors just for any reasons. They need to provide reasons that respect the articulation and the reality constraints as the UN defines them. As such, protective measures taken by individual actors, that have consequences for other actors, should still be founded upon a common ground for justification, while within the constraints nation states are accorded the freedom to rely on their own specific perspectives on the acceptability of risk and often also on the way political values should be implemented.

In the remainder of this dissertation, the UN approach will be taken as exemplary for analysing the other cases. Concerning the reality constraint, this implies a comparable identification of relevant form features of scientific practice. With regard to the articulation constraint, the form features will be more Europe-centered in their operationalisation. The form features of political decision making can be universalized at a very general level, such as in the Universal Declaration of Human Rights, while differences are very likely to arise in a specific implementation in a particular context of local political decision making. How these values are operationalized will become clear in the discussion of the other two case studies.

### **4.5.2. Burden of proof**

I will now consider the issue of the burden of proof in this context. Both approaches put the burden of proof on the party seeking to demonstrate a harm, hence on the party seeking to halt a specific technology. Unless the reasons for



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halting a technological development can be justified, the development should be considered acceptable.

This allocation of the burden of proof puts the external autonomy of the party advancing a technology above that of the party seeking to halt the development of a technology. There appears to be an underlying assumption that developing a technology constitutes an act that is worth protecting as an act of freedom, while protecting oneself against risky technologies is considered to be a potential threat to freedom. Hence, the act of protecting oneself is considered to need justification, while the act of developing a technology is not.

As such, both the UN and the WTO policy can be said to exhibit a technology bias. They favor development of technology over refraining from developing a technology. This bias might also be conceived of as a power bias, because it favors the more powerful parties. Those with the resources to develop a technology are usually more powerful than those without such resources. This is at least the case in the relation between developing nations and developed nations.

As Shrader-Frechette has argued (see Schrader-Frechette: 2002) such a technology bias is unsubstantiated. It is unclear that technological development will generally bring more benefits than lack of such a development (pp.29-34). Considering respect for autonomy, it should be considered an open question whether technological development deserves the benefit of the doubt. Each party will give a different answer for different technologies. Respect for autonomy dictates that such answers should be left to the individual actors.

This implies that the burden of proof about the (alleged) risks associated with a specific technology should be equally divided. Neither the development of technology nor refraining from such developments should be favored in the decision to allocate the burden of proof. This gives all parties involved the opportunity to contribute to the decision regarding a desirable course of action. As argued before, in the allocation of the burden proof, the divergent capacities of the relevant actors should be of paramount importance. Those parties most capable of producing the required evidence should carry this burden. In this case it might imply that developed nations and the biotechnology multinationals should carry the burden of proof. An important additional requirement is that the criteria for evidence of harm are constructed deliberately with all actors party to the decision making so that the party providing the evidence does not interpret the criteria for evidence of harm according to its particular needs.

#### 4.6. Conclusion

The UN approach acknowledges the differences in moral frameworks between nation states arising from their respective identities by allowing nation states to make decisions with regard to risk according to their own perspective. In this way, the UN respects the internal autonomy of nation states whereas it might be said that the WTO approach undermines the internal autonomy of individual nation states by assuming that risk can always be represented in a conclusive way. The WTO approach indicates a pre-occupation with external autonomy at the expense of respect for internal autonomy. Its approach specifically favors the external autonomy of producers of technology at the expense of the internal autonomy of those parties seeking to protect themselves against possible risks associated with technological development.

Since risk assessments leave much room for subjective judgment, to provide conclusive evidence of a specific risk, can be very difficult, if not impossible, especially considering the capabilities in this respect of some developing nation states. This denies other parties the possibility of taking action against risks that fit their particular moral framework. The focus on sound science furthermore denies the differences in capacities between different nation states.

The CPB offers the basic contours for a policy of procedural risk assessment. Such an approach does not beforehand exclude specific contents of risk assessments, as a more substantive approach might do, but does at the same time require that risk assessments made are in accordance with the form features of scientific practice. This process takes into account that cultural values often have an important influence on risk perceptions. It further acknowledges that the (cultural) identity of actors does not impede their autonomy, but rather forms a necessary condition for exercising autonomous choices.

To do justice to internal autonomy, the range of risk representations considered valid considerations for safety regulations should be extended to include more than just scientifically proven representations of risk. The kinds of representations falling in this extended range still require justification, but not necessarily scientifically conclusive justification.

There is some sense in the objective of the WTO's attempt to strive for an international approach to the protection of external autonomy. Abuse of the PP should be avoided and therefore an account of valid and invalid reasons for refusing certain products is desirable. The content of risk assessment, as defined by specific cultural assumptions typical to a nation state, should be allowed to

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vary, whereas the form of the risk assessment should comply with basic scientific epistemic values. Such a procedural assessment of risk is what is strived for in the CPB: nation states have to provide support for their refusal to import certain products, but, in contrast to the WTO approach, without the demand that this support is conclusive.

In this way, some reconciliation between external and internal autonomy can be achieved. The subjective perspectives of different nation states are taken into account, but not indiscriminately so. The claims put forward as autonomous claims are subject to the criteria of credibility, coherence and compliance with scientific rationality. As such, the import of GMOs cannot be interfered with for just any reason. In this way, the external autonomy of traders is still respected. However, the internal autonomy of nation states takes precedence as they are the dominant governors of their territory, and rightly so, as they are the ones responsible for this territory.

Decision procedures on the acceptability of risk could be improved even more if the exporters of a technology are likewise required to provide support for their claims concerning risks and the benefits of their products, i.e. if the burden of proof is divided equally between the different parties. In this way, there is no presumption in favor of the external autonomy of parties seeking to push through a new technological development. In many national contexts this is common practice, as developers of technology are required to provide some evidence with respect to risks associated with their product.

# 5 The case of mass vaccination in the Netherlands<sup>1</sup>

## 5.1. Vaccination and autonomy

The incidence of diseases such as polio, diphtheria, hepatitis B and meningococcal disease substantially decreased globally in the twentieth century, specifically in developed countries. Several factors have contributed to this decrease, such as improved sanitation and widespread vaccination.<sup>2</sup> Although the benefits of vaccination are generally believed to outweigh the potential costs in terms of damage, an increasing number of concerned parents refuses to have their child vaccinated or decide to follow a non-standard vaccination programme. The success of any vaccination programme depends on widespread compliance. Individual non-participation in the programme is therefore undesirable. Since vaccines are not one hundred percent effective, all individuals who opt out of a programme increase the risk for those who are vaccinated. Herd vaccination, i.e. when the optimum vaccination percentage for a population is achieved or exceeded, can be achieved when compliance with vaccination programmes is high. Once herd vaccination is achieved, the chance that the disease will surface and attack vulnerable groups is greatly reduced.

The value of respect for autonomy is an issue in this context. Individuals have personal reasons for evading vaccination programmes. Should they be allowed to act on those reasons? T. Dare claims that there is no ethical problem when people evade the vaccination programme, because the numbers that do not comply are few compared to the vaccinated herd (see Dare: 1998). Such a small minority of defectors will *de facto* not endanger the effectiveness of the programme. From this perspective their appeal to the value of respect for autonomy is easily met.

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<sup>1</sup> An abridged version of this case study has been published in Asveld (2008a) together with elements of chapter 3.

<sup>2</sup> World Health Organization (WHO). 2005. *Immunization against Diseases of Public Health Importance*. Geneva: WHO. Available at: <http://www.who.int/mediacentre/factsheets/fs288/en/index.html> [accessed 21 June 2007].

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I will argue however that autonomy is not just a matter of making a choice and carrying that through, autonomy is also about making a choice for the right reasons. People have their own motives for evading vaccination programmes. These can be divided into three main categories, namely one, religious motives, two, so-called free-riding motives and three, motives stemming from a particular risk perception (see Dare: 1998). Considering the value of respect for autonomy, some of these reasons are worthy of respect, even if this respect implies a slight increase in the risks imposed on others, whereas others can be dismissed as unconvincing.

I will first describe the risks involved and the divergent perspectives on these risks. In the previous chapter I discussed how consideration for identity impacts on respect for autonomy in decision procedures on the acceptability of risks. Respect for autonomy should lead to decision procedures that are open with respect to the content of various risk representations, while maintaining a strict approach with regard to the form of risk representations, i.e. compliance with basic scientific epistemic values. In this chapter I will again consider the relevance of identity for decisions on the acceptability of risks. In this case I will more critically examine the various identities and the associated perspectives on risks to show the discriminatory force of the articulation and the reality constraints.

### 5.2. The debate

#### 5.2.1. Risks

The description of the risks put forward here relies primarily on mainstream perception of these risks. That is: this perception is shared by established institutions such as the World Health Organisation (WHO) and EU and USA officials.

Vaccines are used to provide protection against diseases such as polio, diphtheria, tetanus, pertussis, hepatitis B and meningococcal meningitis. Since the 1940's, when vaccines started to become widely available, they have been administered in large scale mass immunisation programmes in many nations. In some European nations and in the US, compliance to these programmes is compulsory. In other countries, such as the Netherlands and the UK, compliance is voluntary. About twenty years ago, a triple vaccine against

measles, mumps and rubella (MMR) was added to most of these programmes.<sup>3</sup> The benefits of protections against polio are quite clear. This disease can have debilitating effects and it can kill you. Diphtheria, hepatitis B and meningococcal meningitis can also be lethal. The MMR are less often severely detrimental, but devastating effects can still occur for both adults and children, such as infertility, deafness and birth defects for unborn children.

Vaccines consist of weakened or killed strains of a disease. These vaccines provide the body with a physical memory of the disease. This memory consists of anti-bodies to fight off the disease. So once a vaccinated individual encounters these diseases in real life, she will be prepared. However, vaccines are neither 100 per cent effective nor 100 per cent safe. Some individuals do not respond well. This implies they either do not develop the anti-bodies as they were expected to, or the vaccine itself makes them very ill. Cases are known of children exposed to vaccines who suffered severe adverse health effects and where their parents have been paid compensation.<sup>4</sup> This tragic effect occurred with oral polio vaccines for example, which by now have almost entirely been replaced by alternative, safer polio vaccines. Moreover, some people can not, for medical reasons, be immunized. They may have a particular medical condition that prohibits them to undergo vaccination or an allergy for one or more of the adjuncts of a vaccine that means not being vaccinated on balance is safer for them than vaccination.

Since vaccination does not provide 100 per cent protection, the risks of infection continue to exist. With diseases that spread from human to human, total eradication of the disease would be the safest strategy to follow, as is almost the case for small pox. In this way, individuals for whom vaccinations does not work are still protected. This objective can only be achieved through herd vaccination, implying that so many individuals have been immunized against a specific disease that the disease ceases to be found anywhere in the world. Those who are not immunized against a disease are then protected due the effect vaccination has had on those around them. For instance, Europe has been virtually polio-free for several decades. However, small outbreaks keep occurring,

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<sup>3</sup> Rijk Vaccinatie Programma 2006 Over het RVP Available at: [www.rvp.nl/rvp/rijks\\_vp/](http://www.rvp.nl/rvp/rijks_vp/) [accessed 10-february-2006]

<sup>4</sup> Health Resources and Service Administration (HSRA). 2006. National Vaccine Injury Compensation Program, Post-1988 Statistics Reports. Rockville, Maryland: HSRA. Available at: [http://www.hrsa.gov/vaccinecompensation/statistics\\_report.htm](http://www.hrsa.gov/vaccinecompensation/statistics_report.htm) [accessed 09 February 2006]

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especially among the non-vaccinated population. The disease may still enter Europe for instance via travelers. If it does, it can still bring havoc amongst those non-resistant to the disease. This effect is not relevant in the case of tetanus, which does not spread from human to human, but via spores through an open wound that is contaminated.

### 5.2.2. Claims

In the Netherlands, compliance to the state immunisation programme is voluntary and varies between 95 – 97 %. Three main categories of reasons can be discerned for parents choosing to opt out from a vaccination programme.

- (A) Religious reasons
- (B) Free-riding
- (C) Different risk-perception

#### (A) Religious reasons

Some people refuse to have their children vaccinated because they believe health and diseases are products of divine providence. Having one's child vaccinated is considered to be a breach of faith, as can undergoing other medical treatments such as a blood transfusion.

#### (B) Free-riders

This category consists of people who accept the risks as presented by health officials, but who do not wish to subject their own child to the risks of vaccination. These people can be said to take advantage of herd-immunisation without accepting the individual costs of achieving such herd-immunisation. Although this group of people will not usually call their own motivation by the term free-riders motivation, but as a particular effort made by parents to keep their children safe, there is undeniably an element of free-riding. That people may be unable to recognize this element of their argument, does not make it less central to their arguments. Therefore, although this group might not characterize themselves as such, the term free-riders still applies. Free-riding characterizes their behavior best in this specific situation. As will become clear from my discussion of autonomy below, for a claim to be recognized as

autonomous, it needs to describe the behavior of an actor as coherently and understandable as possible, in this case the description of free-riding.

### (C) Different risk-perception

Some people refuse to have their children vaccinated because they perceive the balance of costs and benefits differently than presented by the authorities offering the vaccines. Basically, the argument is that the risks of the diseases are exaggerated and that the risks of the vaccines are being downplayed. Not all who refuse vaccination or fail to comply to vaccination programmes fit exactly into one of the above categories. Some combine arguments, or select a set of arguments only particular kinds of vaccination. For these individuals, the analysis made here is still relevant, as the assessment of their position is indirectly also included in the assessment of the three above categories, even though they represent a diverging version of the original categories.

Notably, people in categories A & B do not reject the official risk representation. They feel solely that they can legitimately exempt themselves from the immunization programme. Their claim, which can be understood as a claim to the right to be respected in their autonomy, is therefore not in potential conflict with other claims in relation to reality constraint. This claim may, however, conflict with the articulation constraint. For category C, a potential conflict with other claims in relation to the reality constraint does exist. I will now systematically discuss all three categories on both constraints.

Are people legitimized in refusing vaccinations on the various grounds they put forward? Individual freedom is of paramount importance in our society. An important element of the argument of the anti-vaccination camp is that they have a right to choose whether they want to vaccinate their child.<sup>5</sup> However, not all claims to the right to be free, to be respected in one's autonomy, deserve equal respect; such claims, especially when such they imply a harm for other parties, should be considered carefully. Seen from the light of the narrative model: To what extent are the different claims put forward in this debate actual

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<sup>5</sup> This discussion would be more complicated and more true to the actual situation if the interests of the child were considered separately. For the sake of the argument however, the interests of the child are considered to be sufficiently protected by the decisions made by its parents.



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claims to the right to have one's autonomy respected? This analysis is focused primarily on the debate in the Netherlands.

### 5.3. Public debate

To answer this question, I will start with a discussion of the claims made in the public debate on vaccination and their tenability in terms of the two constraints. This debate concerns mainly the divergent perspectives on the risks and their acceptability. These perspectives are in this case strongly intertwined with the political claims. The political claims include demands for courses of actions that have direct consequences for other people. If my perspective on health and risks prevents me, or causes me to be (religiously) prohibited from undergoing vaccination, this will have direct consequences for other people in the same vaccination programme.

The main distinguishing quality between the public and the political debate should in this context be understood as relating to the specific kind of identities from which individuals make their claims. In the public debate, this is from their particular, non-political identities mother, member of a religious group, vegetarian etc. In the political debate, participants are expected to act in their capacity as citizens.

The articulation constraint is considered relevant to both types of debate, although in different ways for each debate, whereas the reality constraint is considered to be specifically relevant to the public debate. For a thorough discussion of these constraints, see section 3.4.

#### 5.3.1. Articulation constraint

As mentioned above, in the public debate, the articulation constraint mainly concerns the articulation of one's identity as a motivating force in one's perspective on a specific risk. The articulation constraint requires that individual motivation is coherently articulated in a way that is intelligible and meaningful to other participants in a debate, while specific interpretations of identity should not be enforced upon other people. Additionally, all participants should respect the form features of particular (public) identities. For a more elaborate discussion see chapter 3, section 4.2.1. This implies that some aspect of a particular identity may not be contingent on the specific interpretation of the individual, but rather that the individual needs to articulate her identity within

the contours of these form features. These form features indicate those aspects of identity that are shared and acknowledged by all individuals within a society. Only those positions that meet the demands of the articulation constraint deserve respect by other participants in a public debate as autonomous arguments. The divergent positions in this case shed an interesting light on the applicability of the articulation constraint.

### 5.3.1.1. □ Authenticity and religion

The specific kind of claim of religiously motivated people, which is basically a claim to be respected in their religious identity, raises questions about appeals to be respected in one's identity and how the authenticity of such claims can be determined. In other words: Can the articulation constraint distinguish between sincere and insincere narratives? Any individual may claim to have a religious background which may, according to the requirements of respect for narrative autonomy, exempt him from certain risks. A claim to be thus motivated is difficult to evaluate. Such a claim may be abused to conceal a free-riding motivation. What exemplifies an authentic religious motivation?<sup>6</sup>

Should the individual be a member of a traditional, well-established religious institution, her identity as a religiously motivated person is clearly defined. In the Netherlands, the group that rejects vaccination for religious reasons is actually clearly identifiable because they are members of established, well-known religious communities. This group is easily identifiable by their distinctive lifestyle characterized by religious practice, active membership of a church often accompanied by a typical dress-code. That their belief system contains elements involving a higher being that influences their perspective on the desirability of medical interventions can be considered intelligible and meaningful to other participants.

However, the form features of religious identity are in general rather weak. There are no strict form features of religious identity an individual life should exhibit to be considered genuinely religious. Hence, there are no socially irrefutable features that convey the authenticity of this claim to other individuals. Being a member of a religious community for instance is strictly speaking not a

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<sup>6</sup> I understand authenticity to imply sincerity in describing one's identity. I do not consider the issue of whether this identity is truly one's own or possibly the result of distorting influences such as indoctrination. What the individual believes to be his true identity at a specific moment, will be taken to be the authentic version of that identity.

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form feature of a religious identity. An individual may also claim to be religiously motivated while not being a member of a recognizable community. He may instead have developed his own singular religion of which he is the only member. There is no theoretical or practical necessity for a religious person to be part of a community. This may be said for other qualities that usually determine a religious identity, such as a specific dress-code. They are not necessary elements of a religious identity. Even the belief in a higher deity is problematic as a form feature of religious identity, for example we usually consider Buddhism to be a religion, yet it does not involve belief in a deity. Moreover, there may be all kinds of spiritual vocations that do not include a formal deity, such as some new-age movements, that impact upon an individual's perceptions on the acceptability of specific risks. Such spiritually defined identities may in principle also be considered a legitimate ground for exemption. The existence of this wide array of divergent spiritual perspectives, which are somewhat comparable to religious vocations, makes it even more unlikely that form features can be established for religious and/or spiritual identities.

In the context of religiously or spiritually motivated claims, the form features have little impact on determining the validity of claims put forward, as there are no identifiable form features at stake. It is difficult to find a common denominator for religious and spiritual motivation that could serve as a form feature. Hence it is difficult to assess the sincerity of a claim made by an individual that she is religiously and/or spiritually motivated and therefore has a legitimate reason to be exempt from specific kinds of risks on the basis of form features as there are no discriminating form features.

However, the other requirements of the articulation constraint, such as intelligibility, meaningfulness and coherence, can be expected to serve as discriminatory points of reference. With regard to intelligibility, there are some qualities of religions that help to convey to others one's religious identity. Being a member of a religious community is an intelligible, meaningful content feature of religious identity, even though it is not externally dictated or theoretically derived. Most religions are organized as communities of several people. Membership in such a community will aid the intelligibility of the narrative that constitutes one's religious identity.

Additionally, a specific degree of coherence in the underlying narrative will also support the credibility of one's religious identity. As autonomous claims are assumed to take root in the narrative of an individual's life, religious motivation

has to fit the overall structure of an individual's life. An individual has to exhibit this religious motivation as a guiding principle in her life. A person who has never exhibited any interest in religion whatsoever, and who claims to be suddenly converted will need to provide a narrative that can make sense of such a sudden change. In contrast, the religious identity of individuals who have been known to be religious for a longer period of time can be expected to be more readily acknowledged by other participants in a public debate.

It seems that in this context it is hard to determine beyond doubt the authenticity of a claim to be religiously motivated and hence to the right to be exempted from certain risks. However, it is possible to assess such claims to some extent using criteria such as intelligibility, meaningfulness and coherence. I assume that in public debates on the acceptability of risks the authenticity of religiously motivated identities will have to be determined deliberately, i.e. in open conversation with other participants in the debate.

### **5.3.1.2. □ Intelligibility and free-riding**

With regard to the free-riders group, a different concern arises, related to the intelligibility aspect of the articulation constraint. Not all members of this group will identify themselves as free-riders. However, their motivation appears to be most aptly described by this term. If a child remains unvaccinated in a Western country such as the Netherlands, the risk for that child of contracting diseases such as polio are minimal to non-existent because almost everyone in his direct environment will have been vaccinated. From the perspective of a concerned parent, it can make little sense to subject his child to the risk of vaccination, when the incidence of detrimental diseases has dwindled dramatically. The position is characterized by an acknowledgement of the representation of risk that provides the rationale for the vaccination programme, while refusing to undergo those risks, because the benefits are negligible.

The free-riding element in this line of thought is that the incidence of detrimental diseases has dwindled precisely because large parts of the population have been willing to undergo the comparatively small risks of vaccination. If other people would not subjected their children to the risks of vaccination, the whole line of argument collapses. The risks of non-vaccination will increase considerably if more people who opt out of vaccination programmes. Hence, this position depends on other people being willing to take

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part in vaccination programmes: and hence the above motivation can be seen as a free-riding motivation.

Here the discriminatory force of the articulation constraint in the public debate becomes clear. If members of the free-riding category fail to acknowledge the free-riding element in their position, their claim should be considered to lack on the requirements of the articulation constraint. Without the reference to the free-riding element, the articulation of the motivations misses an explanatory force, it becomes less meaningful. Why would anyone subscribe to the risks and benefits associated with vaccination while simultaneously rejecting vaccination? Such a position is not coherent unless the free-riding element is incorporated.

The claims of individuals who do not acknowledge the free-riding element in their motivation, do not have to be treated as autonomous claims because these claims fail to express motivation intelligibly and meaningfully. Should the free-riding element be acknowledged by members of this group, the claim can be recognized as an autonomous claim. However, free-rider motivations are problematic in the political debate as we will see below.

### 5.3.1.3. Holistic worldview

As described above, people who do not participate in immunisation programmes because of a divergent risk perspective are usually involved in a specific, so-called 'alternative' lifestyle (see Plochg & Staa: 2002). This alternative lifestyle can include the use of homeopathic medicines, organic foods, 'natural' health products and a critical stance towards modern society, which can include strongly developed environmental awareness. Anthroposophist and homeopathic views on health are prevalent. This lifestyle will be termed 'holistic' here: because the views of such people on health and disease diverge strongly from the rational underlying a vaccination programme, vaccinations do not fit into a holistic lifestyle. This point will be more extensively discussed when I discuss the reality constraint.

This different risk perception is motivated from a specific worldview, comparable to the religiously motivated groups. In the Netherlands the Dutch Association for Critical Vaccination (Nederlandse Vereniging voor Kritisch Prikken, NVKP, translation mine) is the most important mouthpiece for this view. However, the common identity for this category appears to be even less coherent and identifiable than that of the religiously motivated, as the main

denominator for this category consists of the alternative risk perception and not necessarily of an alternative world view.

However, there is a specific narrative that can be ascribed to this particular group in general. This narrative consists of suspicion towards modern science and technology, which are considered to be forces that can undermine the delicate balance between nature and humans. As one anti-vaccination site puts it: ‘Whom do you trust? Nature or Man?’<sup>7</sup> This suspicion is further enhanced by conspiracy theories regarding the role of big pharmaceutical companies in alliance with most governments of modern Western nations (see Wolfe & Sharp: 2002; Davies, Chapman & Leask: 2002; Lanctot: 1995). This suspicion results in the embracement of ‘natural’ products and medicine such as produced by using homeopathic and organic production mechanisms.

With regard to the articulation constraint in the public debate, there is no ground to dismiss this narrative. To claim that technology disturbs natural balances and that big pharmaceutical companies are not entirely trustworthy remains well within the range of what can be considered meaningful, intelligible and coherent. Many technological developments have led to severe environmental degradation and many pharmaceutical companies have questionable marketing strategies (see Moynihan *et al.*: 2002). The move to include governments in Western nations in conspiracy theories may be stretching things a bit to some people, but the overall narrative is still comprehensible. The problem with this narrative is not with regard to the articulation constraint, but as we will see below, with regard to the reality constraint.

### 5.3.2. Reality constraint

The credibility of a specific narrative identity depends on its adherence to both the articulation and the reality Constraint. In the approach developed here, the reality constraint basically implies compatibility with the relevant body of scientific knowledge.

The reality constraint is particularly relevant with regard to the last category C: those motivated by a different risk perception. The people in the A and B

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<sup>7</sup> Vaccination Information Service, available at: <http://www.vaccination.inoz.com/homoe.html>, [accessed 20 February 2006].

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categories are not motivated by a view on the scientific reality that diverges from the view underlying the immunisation programme.

The religiously motivated are compelled by a specific kind of faith, which may very well be compatible with the relevant body of scientific knowledge. Science as they perceive it has nothing to do with their motivation. This group actually seems to agree with the mainstream representation of risk, they mainly disagree about the acceptability of that risk because of their faith. Their faith is independent of scientific knowledge. The free-riders are motivated from exactly the same perspective on the risks involved as forms the basis of the immunisation programme. Hence for these two groups there is no disagreement with other individuals on the contents of the shared reality. Both non-compliers and compliers accept a similar representation of risk: a representation that is compatible with relevant scientific knowledge.

However, in the case of the third category C, the non-compliers are motivated by at least a partially different perception of the risks involved, as will be related below. Not all non-compliers of vaccination programmes, and who are motivated by a different risk-perception will subscribe to all the elements mentioned below. Many individuals forego only some vaccinations and only for some of the arguments given below. However, since the arguments of such individuals consist primarily of elements of the view outlined below, they will be considered to be represented in the analysis of the overall view.

The question is whether this divergent perception of risk concerns content or form features. As long as this risk perception does not violate the form features of science, it should be allowed within the debate on the acceptability of risks associated with vaccination. The form features of scientific knowledge consist of traditional epistemic values. These include: empirical support, simplicity, coherence with other (accepted) hypotheses, explanatory and predictive power, reproducibility and accuracy.

The risk perception of the objectors to vaccination programmes can be broadly summarized as follows: the cure is worse than the disease. Diseases are not as harmful as health authorities allege them to be. They strengthen the immune system, whereas vaccines actually ruin the immune system because they bypass the natural barriers that protect the human body against infectious disease. These natural barriers include the throat and nostrils. The fragile immune system of a child is not able to handle the extreme doses of antigens injected into the blood in the form of vaccines. As a result, new diseases such as

allergies and autism are rampant in tandem with the increasing use of vaccines. In other words, a causal link is assumed between these phenomena (see Prent & Schaper: 2003). Vaccines are furthermore supposed to give rise to the non-specific stress syndrome, which can be linked to various detrimental health effects, including cot death and shaken baby syndrome (see Scheibner: 1993).

Vaccines are also considered detrimental because they are made up of harmful elements such as formaldehyde and aluminum phosphate. Additionally, the production of bacteria and viruses for vaccines is questionable. It involves the use of kidney cells taken from apes, particularly in the polio vaccine. This may have given rise to the spread of AIDS (see Prent & Schaper: 2003). Additionally the claim is that other, natural remedies, such as homeopathic medicine are more apt to tackle diseases in general. Finally, today's standards of improved hygiene and food quality are assumed to have reduced the deadly nature of some of the diseases against which children are vaccinated. Therefore, the need for vaccines is questionable (see Ankum *et al.*: 2001).

This view on vaccinations and diseases is based on a strong belief in the self-recuperating abilities of the human body, aided by 'natural' products. It relies on a perceived balance between health and disease in which diseases can be a burden, but are essentially beneficial. However, this view is likely to be an idyllic illusion rather than a well-founded perspective on reality, as we shall see. The *content* of this view is clear and apparently consistent. However, whether this view is entirely convincing depends on the quality of the supporting evidence and that quality can be determined by the form features of the evidence. For important elements of this view, the form features are lacking in several respects.

One of the main proponents of the above-mentioned view is Dr Viera Scheibner. Her work can be regarded as illustrative, as exemplar material for the group of objectors described in this section. The material of the NVKP is mostly based on Scheibner's book: *'Vaccination, 100 years of orthodox research shows that vaccines represent a medical assault on the immune system'*. Scheibner claims to have monitored the breathing movements of young children through a self-made device right after they were vaccinated. She claims she has a substantial number of observations that show that children's breathing rates accelerate after vaccination. She explains this by reference to the Non-Specific Stress Syndrome. She then links this syndrome to both cot death and to the shaken baby



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syndrome.<sup>8</sup> This syndrome is not caused by physical abuse, as is generally believed, Scheibner claims, but occurs because of vaccination (see Scheibner: 1993, 41).

In her book Scheibner claims to be able to support most of the common anti-vaccination arguments on the basis of orthodox medical research. She claims for instance that the rate of cot death in Japan diminished substantially after the vaccination for pertussis was raised to two years of age. Her sources stem from a diverse range of journals, among which established journals such as the *British Medical Journal*.

However, empirical support for her argument is dubious. For instance, her claim that the rate of cot death in Japan diminished is based on reports by parents of adverse health effects associated with vaccination. Cot death occurs by definition in the first twelve months of an infant's life. If vaccination is given from age two and onwards, it is to be expected that the *reports* of cot death associated with vaccinations disappears. The decrease of such reports do not support the thesis that vaccination caused cot death (see Leask & McIntyre: 2003). This claim by Scheibner is not supported by the evidence: one of the form features of scientific practice.

Scheibner has no formal medical training. She is trained as a palaeontologist. She has co-authored one medical article between 1966 and 1996 (see Leask & McIntyre: 2003). The scientific robustness of her own research may be questioned. It has never been peer reviewed nor repeated. The machine she used for monitoring the breathing movements of young children has been lost since the only person who knew how to operate it, Scheibner's husband, passed away.<sup>9</sup> The results of this specific research can therefore not be scientifically assessed.

Similarly, in the material put forward by the NVKP many links to so-called 'scientific articles' turn out, on closer inspection, to be nothing more than letters to the editor or viewpoint articles. M.D. Odent *et al.* (1994) for instance, is often referred to as a scientific article in the information material provided by the opponents, whereas it is a letter to the editor (see Odent *et al.*: 1994). W.S. Kyle (1992) is a viewpoint article by a lawyer stating the hypothesis that production of

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<sup>8</sup> The shaken baby syndrome is believed to occur when caregivers shake a baby vehemently, thereby injuring it internally, which eventually leads to death.

<sup>9</sup> V. Scheibner. Dynamics of Critical Days as Part of the Dynamics of Non-specific Stress Syndrome Discovered During Monitoring with Cotwatch Breathing Monitor, available at: [http://www.acnem.org/journal/23-3\\_december\\_2004/cotwatch-scheibner.htm](http://www.acnem.org/journal/23-3_december_2004/cotwatch-scheibner.htm) [accessed March 24, 2006]

vaccines have induced the onset of AIDS in human beings. This article is used as a basis for advancing this hypothesis in the information material of the NVKP. However, these viewpoints typically have not been tested by rigorous experiments, repetition of experiments and peer review and should therefore not be considered as supported by empirical evidence. Some articles that the NVKP relies on are peer-reviewed, published articles in established scientific journals, but most of them are old and appear to stand on their own: that is to say, they do not accord with other centrally accepted hypotheses on the incidence and causation of risk (e.g. Tonne: 1985).

Many of the arguments are furthermore supported by material from sources such as the *Journal of the American Institute of Homeopathy*. Considering the lack of scientific evidence supporting the effectiveness of homeopathic medicine, it is questionable that the opponents are justified in relying on such a journal to undermine the case for the effectiveness of vaccines, which has been proven in numerous scientific studies. This pattern of misrepresentation of scientific information and/or reliance on unconventional non-scientific sources is common in websites providing information that aims to disqualify vaccination (see Davies *et al.*: 2002; Friedlander: 2001).

Research on the internet indicates that the anti-vaccination camp does have some proponents trained in the medical sciences. As it turns out, most of the opponents who have a formal training either make rather moderate claims about the adverse health effects of vaccines (see Wolfe *et al.*: 2002), or they are controversial, and have sometimes even been expelled from their professional field.<sup>10</sup>

Many of the claims made by the NVKP can be easily refuted. One of the claims made is that every year around 11.000 cases of adverse health effects in relation to vaccines are reported in the US. The NVKP fails to mention that these were solely reports of parents, a causal link between the adverse health effects and vaccines had not been established.<sup>11</sup> The actual number of such cases

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<sup>10</sup> This happened to G. Lanctot M.D., the Canadian author of 'The Medical Mafia' for purposely misleading and frightening the public, thereby abusing her medical degree. She is presented by Prent, an active member of the NVKP, as a renown scientist. Province, C., Glossary of Individuals and Groups Frequently Encountered in Discussions of Opposition to Vaccines and / or Vaccine Policy, available at <http://www.cinam.net/son3-2-cp.html> [accessed March 22 2006]

<sup>11</sup> Vaccine Adverse Event Reporting System (VAERS). Brochure. Available at [http://vaers.hhs.gov/pdf/VAERS\\_brochure.pdf](http://vaers.hhs.gov/pdf/VAERS_brochure.pdf) [accessed March 24 2006]

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recognized by the vaccine compensation system (VICP) of the US government totals 2.000 cases in the period from 1988 to February 2006, for all vaccines.<sup>12</sup>

The arguments presented by the anti-vaccination camp can be said to fail to live up to the reality constraint. Most of the arguments are not compatible with the relevant body of scientific knowledge as they are not based on repeatable, peer reviewed evidence. Instead they are based on a view of diseases that is far more benign than reality, and on a view of immune system development that is not compatible with scientific knowledge. Some elements of arguments are compatible with the relevant body of scientific knowledge, such as the claim that improved sanitary conditions caused lethal diseases to dwindle, however, claiming that improvement in sanitary conditions account for the entire decrease in the incidence of these diseases is stretching this hypothesis beyond what is compatible with the relevant body of scientific knowledge (see Atkinson *et al.*: 2000).

Many of the arguments made are unsubstantiated and often even misrepresentations of the sources. The claims made by the anti-vaccination camp can therefore be rejected by other parties in society. Hence, there is no ground to allow this group not to comply to vaccination programmes.

There are other reasons that may compel authorities not to force vaccination upon such people. These reasons are basically utilitarian in nature. Studies have shown that mandating vaccination does not increase the compliance rate of vaccination programmes (see Dare: 1998): people still fail to comply. Therefore, such measures could prove to be ineffective. Moreover, mandatory vaccination programmes could substantially reduce trust in such programme and fuel the suspicions already prevalent towards such programmes, further threatening compliance.

Effective measures might be more readily found in improved methods of communication. Some of the claims of the anti-vaccination camp are not entirely unfounded. It is true that vaccines are neither 100 per cent safe nor 100 per cent effective. Medical science is sometimes crude and it has its limitations. Moreover, the influence of pharmaceutical companies on medical science is

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<sup>12</sup> Health Resources and Service Administration. 2007. National Vaccine Injury Compensation Programme. Statistics Reports, available at: [http://www.hrsa.gov/vaccinecompensation/statistics\\_report.htm#post\\_1988](http://www.hrsa.gov/vaccinecompensation/statistics_report.htm#post_1988), [accessed, March 30 2006]

worrying. Authorities might gain trust of the non-compliers if these points are acknowledged and addressed in a way that meets the concerns of these parents.

### 5.4. Political debate

In the political debate the articulation constraint is most relevant, as it applies to the political identity of citizenship. As discussed in chapter 3, section 4.4.2, the form features of citizenship consist of compliance with four basic values and the quality of overridingness. These values are<sup>13</sup>:

- freedom
- non-malificence
- justice
- equality

Only the claims of the religiously motivated and of the free-riders are imported as they can be recognized as autonomously made claims. The claim of the free-riders is considered to be an autonomous claim only insofar as members of this category admit to the element of free-riding present in their claim. The claim of those with a divergent risk-perception has failed to meet the reality constraint and as such does not have to be considered an autonomous claim which deserves consideration in a political debate.

#### 5.4.1. Religiously motivated

The religiously motivated defectors may first appeal to the value of freedom, which makes up an important element of the identity of citizens within a modern, democratic society. They may claim they are free to live their life as they see fit. Their claim is recognizable as an authentic claim. These people live their lives ostensibly in the service of God: their identity is to be a deeply religious person. To interfere with their religious practice would seriously interfere with their freedom. However, other citizens may counter this claim with reference to the value of non-malificence or freedom from harm, stating that the safety of the compliers with the immunisation programme is threatened by the freedom of the religiously motivated.

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<sup>13</sup> See chapter 3, section 4.4.2 for a more extensive argumentation for these four values

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There appears to be no easy way to resolve this conflict. Each party may strengthen the weight of shared reasons offered with reference to their non-political identity. The religious objectors may state that the costs of compliance are extremely high for them as it can imply they will suffer in hell for eternity. The compliers might bring forward that, as parents, the thought of one's child suffering is unbearable.

Neither party needs to accept these non-shared reasons the other party offers. They spring from the particular identities of the individuals involved, while the political identity of citizen dictates that the four basic values override all other considerations. However, participants in the debate may be moved by the weight the arguments springing from particular identities carry for the other party. Participants may recognize the authenticity of the claim and the appeal it has for the other party as an element in balancing, for themselves, the conflicting shared reasons. How strongly a specific party feels about a specific claim and how many, conscience-related, problems it might imply for a party to renounce that claim, determines how strongly that party is affected in its capacity to behave in an autonomous manner.

In this case, the form features of political identity do not lead to a solution of this conflict over the acceptability of risks. In different societies, the solution of this conflict will be reached in different ways. Since there is no easy solution available, additional reasons will have to be invoked to settle the matter. In the Netherlands, the freedom of the defectors is accommodated. Compliance is voluntarily. In other, comparable Western countries such as France and the US compliance is compulsory.

### 5.4.2. Free-riders

For the free-riders the issue is completely different. On what shared value can the free-riders rely for justifying themselves? Freedom would seem to be the most appropriate value. The free-riders claim they are free to do as they please. Opposing this claim to the right to be free, stands the claim to the value of equality. If the benefits attached to undergoing a small risk are evenly distributed, than the burdens of carrying the risk should also be evenly distributed. An unequal division of risks and burdens is unjust.

The claim of the free-riders seems on closer inspection foremost a claim to non-malficence. The motivation for not taking part in a vaccination programme

is not one based on a desire to protect a specific way of living or to keep their moral integrity, but foremost to keep one's children safe and healthy without carrying the burdens of that safety. This claim to non-malificence can however never be a truly shared reason in this case as it can only be a reason for a limited group of people. If everybody gave this reason the same moral weight, it would be self-defeating. If we all refused to take part in a mass-vaccination programme for safety reasons, we would have no protection against the diseases vaccinated against. Shared reasons are only acceptable as long as they can be embraced by all members of a community.

This claim of the free-riders is incompatible with the value of equality. It is not available to everyone within a society. It depends on there being only a minority that acts because of this reason. Since the political values override any other considerations in the political debate, the free-riding motive is unacceptable.

### 5.5. Conclusion

Considering the reality and the articulation constraints, the different claims of the anti-vaccination camp are assessed differently. The only claim that has a political impact is the claim of the religiously motivated. Their claim is ostensibly linked to their identity and is not based upon an unsubstantiated risk perception. The claim of the free-riders is self-defeating. It is not compatible to form features of citizenship in modern western society, such as the value of equality. The claim of those motivated by a different risk perception lacks considerably with regard to the reality constraint and hence should not be considered an autonomous claim that should command respect from other people.

This case indicates some of the strengths and weaknesses of both constraints. In the public debate, the articulation constraint does not offer enough criteria to distinguish inauthentic claims entirely from authentic claims, at least in the case of spiritual and religious motivation. This is because spiritual and religious identities lack distinct form features: they are merely characterized by content features that are easily identifiable. These content features allow for some critical assessment of religious identity, but only on aspects such as intelligibility and coherence, which in this context does not amount to a definite judgment.

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Rather, the authenticity of such claims will need to be assessed case by case, deliberately, in public debates.

With regard to the free-riders, however, the intelligibility criterion has more discriminatory force. The claim of the free-riders can only be comprehended with reference to the free-riding element. Hence, the motivation of this group of people can only be considered autonomous under one specific description.

The application of the reality constraint in this case illustrates that not all representations of risks can be considered legitimate within decision procedures on the acceptability of risks. Aside from allowing a wide diversity of perspectives, the reality constraint also serves to distinguish between these divergent perspectives. The position of the group with an alternative risk-representation is interesting, as this perspective violates the reality constraint, but not the articulation constraint. The representation of risk is a central element of this perspective, in contrast to the perspective of the religiously motivated, to which the reality constraint does not apply.

The next case on mobile phone technology in the Netherlands will delve deeper into the specifics of the political debate on the acceptability of risks. This case also brings to light further insights on the articulation and the reality constraint in the public debate. An interesting feature of this next case study is that the requirements of the reality constraint are part of the public debate.

# 6 The debate on UMTS-technology in the Netherlands<sup>1</sup>

## 6.1. Introduction

### 6.1.1. Electromagnetic radiation and autonomy

In the Netherlands, wide-spread concerns on the alleged risks associated with mobile phone technology have stalled the use of the latest technological development in this area: Universal Mobile Telecommunication (UMTS), also known as third generation, 3G-technology. Considering the value of respect for autonomy, what is the moral relevance of these arguments? Proponents may be seen as pushing through a potentially harmful technology, while opponents may be seen as halting the development of a potentially beneficial technology. Both strategies may have severe consequences for others. Considering the quality of the arguments of all parties involved, which course of action ought to be taken?

The opposition to UMTS originates in concerns about its predecessor, the familiar Global System for Mobile Communication GSM. The wide-spread usage of cell phones has sparked health concerns worldwide with respect to the effects of the electro magnetic radiation on which this technology is based. In several European countries, such as Italy and the United Kingdom, and in the United States, concerned individuals have taken action against the placement of phone masts, although in the USA the debate subsided around the time it started to take off in Europe, which was around mid 1990's. In Europe newspapers issued reports on links between cellphones and cancer, and concerned mothers kept children at home fearing the effect of electromagnetic radiation, neighborhoods organized to get rid of local telephone masts, court cases were initiated over the alleged adverse health effects of radiation (see Burgess: 2004).

Interestingly enough, the considerable amount of attention directed at a variety of health concerns did not significantly delay the diffusion of mobile

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<sup>1</sup> This is an extensively extended and adapted version of Asveld (2008b)



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phone technology. Between 1990 and 2000 the number of mobile phone subscribers globally increased by a factor 65. It is estimated that in 2007 3 billion people globally had mobile phone subscription, including prepaid costumers.<sup>2</sup>

This is different for the GSM-successor UMTS. Concerns about adverse health effects have intensified and are more wide-spread than the concerns raised solely with regard to GSM. In the Netherlands, in concordance with other European countries, UMTS evoked fierce opposition. This has resulted in direct hampering of the emplacement of the required support network. Concerned individuals protested against the placement of masts and took to the streets in national demonstrations,<sup>3</sup> several cities restricted the amount and positions of masts within their city borders<sup>4</sup> and in the Dutch parliament questions were asked about the alleged risks attached to UMTS.

Opponents to the technology fear that the Ultra High Frequency Electro Magnetic Radiation (UHF EMR) emanating from the antenna and from the telephones interferes with basic biological processes. The pulsed character of the UMTS signal adds to the worries. However, regulatory authorities in general state that scientific research so far has shown no indication of any adverse effects and therefore protective measures are unnecessary. The Dutch government, as other European governments, continues its strategy of stimulating UMTS technology, but it is increasingly confronted with opposition from concerned groups, including city councils.

The current situation is problematic with regard to respect for external and internal autonomy. Risks are imposed on people without their consent and their perspective on the alleged risks of mobile phone technology are not taken into account. However, the elimination of these risks may prove problematic for the external autonomy of other individuals, as they are deprived of the benefits of mobile phone technology, or at least of some aspects of it, if the GSM structure is maintained, but the UMTS-structure is abandoned.

It is argued here that, taking into consideration the demands of respect for narrative autonomy, further evidence should be gathered on the alleged health risks of mobile phone technology, based on criteria for evidence of harm that can be shared by the parties involved. The responsibility for obtaining this evidence

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<sup>2</sup> <http://www.icinsights.com/news/releases/press20060918.html>, accessed oct 4, 2006

<sup>3</sup> On the 16<sup>th</sup> of April 2005, a national demonstration was organized in Amsterdam

<sup>4</sup> <http://www.nu.nl> (accessed 27<sup>th</sup> of April, 2005), Financieel dagblad, April 16<sup>th</sup> 2005

should be with the authorities and the providers. Evidence obtained according to this procedure should be used to inform the political decision making process.

To gain more insight into the intricacies of this debate, first the different actors involved will be listed below, along with a short description of their position. Secondly, the different arguments of the actors will be discussed. The arguments in the public debate concerning the quality of the scientific evidence will be discussed in section 2, followed in section 3 by a discussion of the arguments concerning the desired political course of action.

### 6.1.2. Empirical data

The analysis of this case is partly based on interviews with representatives of the parties identified below and partly on resources such as internet-sites (mainly [www.stopumts.nl](http://www.stopumts.nl)) and books and articles. One representative was interviewed from each of the parties below: a representative of the government from the Dutch ministry of Housing, Spatial Planning and the Environment from the Directorate Chemicals, Waste, Radiation Protection; a representative of a large Dutch operator, both of these agreed to be interviewed on the condition of anonymity; the honorary secretary of the standing committee on Radiation Protection of the Health Council: Eric van Rongen and Mr Gerrit Teule as a representative of the opponents to UMTS.<sup>5</sup> The representation of the arguments is based on these interviews and on the written sources.

### 6.1.3. The parties involved

This section contains an overview of the parties involved in the UMTS debate in the Netherlands and their general points of view. The division between proponents and opponents is very rough, as the different positions are more nuanced, especially for the proponents-camp, than is reflected in this crude division. However, these are the opposed actors, and as such it can be an informative division, which is why it is included here.

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<sup>5</sup> Transcripts of these interviews are available.

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### Proponents:

*Government:* the government auctioned the UMTS frequencies and is ultimately responsible for establishing the safety norms. The government recognizes its duty to take concerns of citizens seriously, however valid or invalid the reasons for these concerns may be.<sup>6</sup> Balancing out the different interests and sentiments that are relevant in this case, the government takes the position that there are no reasons to take precautionary measures, as the available scientific knowledge at this point does not provide convincing evidence of risks. The government is willing to invest a limited amount of money in research.<sup>7</sup>

*Health Council (HC):* the main advisory body to the government. The HC provides the basis on which safety norms are established. The point of view of the Health Council largely coincides with that of the government with regard to the need for precautionary measures although the Health Council advised that more money should be invested in research.<sup>8</sup>

*Operators:* these are the companies that operate mobile phone technology. These companies are usually willing to invest in research concerning possible risks attached to mobile phone technology. They have a strong interest in a smooth enrolment of the third generation mobile phone technology, and they do not see reasons to take any precautionary measures, as the evidence for risks is minimal.<sup>9</sup>

*Users:* many individuals use mobile phone technology, but they generally do not have an individual voice in the debate on the safety of this technology. Their

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<sup>6</sup> A government official of the relevant Dutch department explained this in an interview, april 8<sup>th</sup> 2005

<sup>7</sup> In 2007 the new minister responsible for health and environmental affairs decided to spend 16 million euro on research into the risks associated with mobile phone technology. This is considerably more than was envisioned at the time when this research was conducted. This extra money does not shed a radically different light on the position of the government, it solely indicates that its position has shifted somewhat. I will therefore not explicitly consider this additional money here, although I will refer to it in the conclusions.

<sup>8</sup> Information obtained from an interview with Dr. van Rongen, secretary of the Standing Committee on Electromagnetic Radiation of the Health Council, nov 11 2004

<sup>9</sup> Information obtained from an interview with a representative of a large operator of UMTS technology

interests are largely met by the wide-ranging availability of mobile phone technology.

### Opponents:

The camp of the opponents consists of a wide variety of concerned individuals, both laypeople and experts<sup>10</sup>, and more or less organized groups. For instance, in Germany more than a hundred doctors and scientists signed the Freiburg Appeal calling for more caution with regard to EMR. This chapter I focus on an individual, Gerrit Teule, and a group in the Netherlands, whose views can be taken as generally representative for the views of the opponents.

*Gerrit Teule:* he has written several popular books (e.g. Teule: 2002) about the possible adverse health effects of mobile phone technology and the injustices, as he sees them, related to imposing these risks on the general population. He is a concerned, independent individual with a background in the engineering sciences.

*The Stop UMTS-website:* this website ([www.stopumts.nl](http://www.stopumts.nl)) was founded by Mr Ewald Goes and is maintained by several people. This website reports on developments concerning the enrolment of third generation mobile phone technology. It contains links to scientific sources that provide evidence, or indications, of the alleged adverse health effects of mobile phone technology. The reliability of these sources is difficult to establish and probably varies.

## 6.2. The public debate

The public debate concerns disputes about the representation of risk and related arguments concerning the issue of identity. If the arguments put forward in the public debate are considered to be tenable with regard to the reality and the articulation constraint, they should inform the political debate.

The main disagreement between the parties involved in the UMTS-debate relate to a) what the relevant scientific material consists of and according to which standards this material should be assessed b) what the relevant scientific

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<sup>10</sup> Among the opponents are people with a higher education in related technological fields and with positions at universities in relevant fields. One of these people is for instance Prof Lucas Reijnders of the University of Amsterdam.

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material pertains to, or put differently: What actions are justifiable on basis of the scientific material available? The first issues a) are discussed in the public debate. It is understood as making up the public part of the debate as these arguments delineate the different perspectives on the criteria for evidence of harm. These claims will be assessed according to the reality constraint. The parties involved also make claims about relevant identities and associated obligations. These claims will be assessed according to the articulation constraint.

The issue mentioned at b) refers to the political question i.e. given the information on risk associated with mobile phone technology, what possible measures, if any, should be taken to deal adequately with this technology? These issues will be discussed in the political debate which is analysed in section 3.

### 6.2.1. Reality constraint

A main disagreement between the parties involved concerns the criteria for evidence of harm. As will be explained below, there is substantial disagreement between the parties on how these criteria should be applied. This disagreement concerns the *content features* of scientific practice: What should science be about? Additionally there is disagreement about the epistemic values to which relevant scientific evidence should comply, in other words: about the *form features* of scientific practice.

#### 6.2.1.1. The dispute about criteria for evidence of harm

The major issue in the debate on health effects concerns the alleged effects of electromagnetic radiation under the conditions of the mobile digital communication network. Opponents claim that this radiation is far more detrimental than the authorities claim. They state that most of the research done so far has not been performed according to the right criteria for evidence of harm. These criteria may be considered the content features of scientific practice. They relate to issues such as the modeling of the human body, the time lapse envisioned between cause and effect, the kind of effects thought to be likely to result from a specific cause etc.

The radiation emanating from phone antenna is known as Ultra High Frequency Electromagnetic Radiation (UHF EMR).<sup>11</sup> These EM fields include those that are usually produced by human-made utensils including mobile phones and antenna. The dominant convention within science is that heating of tissue is the main health effect arising from this kind of radiation. Mobile phones are considered to be the most probable source for tissue heating.

Opponents of GSM and UMTS antenna contend that worrying effects besides those of heating occur. They claim that radiation emanating from mobile phones and antenna causes various adverse physical effects ranging from headaches, panic attacks and sleeplessness to cancer. These symptoms are assumed to be effects of the EMfields interaction with the human body, which is considered to be an electromagnetic organism, and radiation from antenna and the like. Other artefacts producing electromagnetic radiation are in this view also suspect as sources of physically damaging emittance.

The Dutch Health Council (HC) however considers the likelihood of such effects occurring due to electromagnetic radiation at the frequencies used for mobile communication to be highly unlikely. This opinion is based, the HC states, on the available scientific evidence. The occurrence of additional effects besides the heating of tissue due to UHF electromagnetic fields is not scientifically proven, or at least not sufficiently shown to be plausible. Reliable scientific sources for the HC include peer reviewed publications in established journals that report research that adheres to the values of good science such as reproducibility and compatibility with other scientifically established knowledge.<sup>12</sup> The slight amount of scientific sources that seems to contain evidence to the contrary is either marginal and lacking in quality, or misinterpreted by the opponents.

The opponents say that the criteria for research which would bring out the existence of risks attached to mobile phone technology are not met in most cases. Therefore the evidence about the risks is inconclusive. Criteria for acceptable research according to the opponents are spelled out on the Stop UMTS-site. Such requirements include among others: a focus on long term effects, a control group has not been in contact with radiation for a considerable

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<sup>11</sup> The name Ultra High may be a bit misleading here. It does not imply that this kind of radiation has the highest frequency in its kind, it merely denotes a specific frequency.

<sup>12</sup> As stated by Dr van Rongen, nov 11 2004, and Health Council (2002)

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period of time, or not at all and a focus on the effects of UHF EMR on subtle biological mechanisms.

Some of these criteria have also been put forward by the HC, such as a focus on long term effects. However, the HC maintains its position that enough scientific research has been performed into the risks associated with mobile phone technology to warrant its position that the risks are negligible. The idea is that research already done according to current design criteria offers enough evidence to substantiate the claims about safety. The opponents think that unless more research is conducted according to the criteria they propose, claims about the relative safety of mobile phone technology cannot be substantiated.

The design criteria the opponents propose should comply with the basic epistemic values, form features of scientific practice, to have a serious appeal within the debate. We can consider whether these criteria are tenable or not. Until now, a lot of the research into the effects of antenna has not lived up to these criteria. Many studies about the effects of antenna focus on short-term effects. One study that focused on the long-term health effects in the neighborhood of antenna found an increased risk for cancer, but this study was dismissed by German authorities as failing in methodology<sup>13</sup>. Long-term effects have been studied for mobile phones: the results vary. One study found detrimental effects to the eyeball, some have found evidence of an increased propensity to brain cancer, but this has not been confirmed by other studies.<sup>14</sup> In 2006, the results from a large international case-control study<sup>15</sup>, INTERPHONE into the correlation between extensive use of mobile phones and tumors in the brain were made public. This study was funded by the European Union and the International Union against Cancer (IUGC). The results gave a weak indication of a possible relation between long-term, regular use of mobile phones and the incidence of (benign) tumors (see Health Council: 2006). However, according to the opponents a case-control study is insufficient to achieve certainty about possible adverse health effects. The authorities likewise do not regard such a study to be conclusive.

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<sup>13</sup> Naila research, Federal Office of Radiation Protection, Germany (2005)

<sup>14</sup> Health Council (2003)

<sup>15</sup> A case-control study is an epidemiological study in which patients who already have a disease are studied. The study looks back to see if there are any characteristics of these patients that differ from those who do not have the disease.

Although the results from long-term studies until now have provided little indication that harm occurs due to UHF EMR, there are good reasons to pursue this line of research, as the HC also acknowledges.<sup>16</sup> The recommendation of the HC for more long-term studies was picked up in 2007 by the newly elected government and the new minister of environmental affairs decided to invest 16 million Euro in research into the effects of electromagnetic radiation.

Concerning the demand for a control group: it is very hard to find such a control-group, because the amount of electro-magnetic radiation in our environment has increased substantially over the past few decades, subjecting most people in society to such kind of radiation. The opponents state that a proper control group should have been isolated from this radiation for some period of time to function adequately as a control group. It is argued that research into subtle biological mechanisms can only be properly conducted with the use of such a 'clean' control group and the long term monitoring of research subjects, something which so far has not been conducted in a manner that satisfies the criteria of the HC for good research. In its latest advice the HC mentions research into subtle biological mechanisms as a relevant topic for further investigation.<sup>17</sup>

The dispute about the criteria for evidence of harm does not appear to be irreconcilable. The different sets of criteria are not mutually exclusive, they appear to be complementary. It is possible to do research that lives up to the criteria for good scientific practice, while focusing on long-term health effects. Although the scientific material on adverse health effects related to mobile phone technology produced so far provides little proof for the existence of risk, the possibility cannot be excluded that other types of research will produce such evidence of harm. Although such evidence may be difficult to obtain, it is not impossible, nor is it outside the confines of modern science. The reality constraint does not exclude the perspective of the opponents on the required criteria for evidence of risk as a serious argument.

Although the criteria proposed by the opponents may in some respects be difficult to maintain, these difficulties are not insuperable, nor are the criteria unreasonable. It may be said that the criteria for good scientific practice do not necessarily invalidate the claims of either the proponents or the opponents. The proponents can be said to be conservative in their estimation of the possible

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<sup>16</sup> Health Council (2006, 2003)

<sup>17</sup> Health Council, 2006, pp. 31-36



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risks, but they do not violate the reality constraint. The claims of the opponents can be said to be relatively pessimistic, but they may still be convincing as they do not violate the reality constraint. The only problem for the opponents appears to be the minimal amount of indications of harm, but this might be countered by the additional criteria for desirable research that may lead to additional evidence.

Both positions appear tenable considering the reality constraint and they are even compatible in some respects. A more fundamental disagreement between the two parties however, lies at the level of the appropriate form features of scientific practice, as will be discussed below.

### **6.2.1.2. The dispute on the form features of scientific practice**

As described above, the argument of the proponents is that there is not sufficient indication of risks to health due to mobile phone technology to warrant protective measures. According to the opponents, there is sufficient indication, but the proponents are misguided because they do not value this evidence in the right way. This indicates a disagreement concerning the issue of the criteria for sound scientific practice, or, in my terminology, on the form features of scientific practice.

The HC relies on scientific research published in peer-reviewed journals that complies with criteria for good scientific practice, such as accordance with widely accepted scientific theories, reproducibility, supported by evidence and precision. I have earlier identified these criteria as the form features of the reality constraint.

Based on these criteria, the HC dismisses most of the scientific evidence that appears to indicate any adverse health effects. Sometimes however, the way these criteria are applied appears contestable to the opponents. The opponents know of scientific sources that are peer-reviewed and produced by respected scientists, which indicate adverse health effects, which are none the less dismissed by the HC. The number of these articles is not overwhelming, but they are available. The HC requires more indications than are currently available from reliable scientific sources whereas for the opponents, each indication is enough to stir up their worries again.

The availability of information that contradicts the position of the Health Council, which appears to stem from the same scientific community the HC draws from, creates distrust amongst the opponents of mobile phone technology

towards regulatory authorities. The opponents feel that for some reason, some scientific material is unduly excluded from scrutiny by the HC<sup>18</sup>.

This conflict is basically a conflict about a form feature of science, namely the appropriateness of scientific conservatism. This is related to an avoidance of type 1-errors as opposed to avoiding type 2-errors. Type 1-errors refer to acceptance of a false positive; type-2-errors refer to the acceptance of a false negative. Avoiding type 1-errors is part of conducting good science. Before something is added to the existing body of scientific knowledge, it has to be well established. We want to be careful not to be too hasty in accepting something as true, hence the conservatism that is common among scientists and that is reflected in the attitude of the Health Council. Avoiding type-2-errors implies we are careful to reject the existence of a specific phenomenon mistakenly, such as a causal relationship. For the opponents, avoiding type-2-errors is most important. They are very reluctant to dismiss the possibility that EMR causes adverse health effects, when there are indications that this possibility exists.

The criticism by the HC on scientific evidence indicating harmful effects of EMF boils down to questioning the interpretation of the results. A common allegation uttered by the HC is that the findings do not justify conclusions about the existence of adverse health effects.<sup>19</sup> Although the findings could be explained by the postulation of adverse health effects, they could also be explained by additional factors that cannot be entirely excluded due to some flaws in the research set-up. As long as such additional factors can also explain the results of a specific experiment, or as long as results have not been reliably reproduced yet, for whatever reasons, the results of an experiment are not taken as support for the existence of adverse health effects.

The opponents however think that even the slightest indication of the possible existence of adverse health effects should be taken seriously, even if alternative explanations are conceivable, especially since the opponents suspect that the relative low amount of publications indicating adverse health effects is caused by biases in research strategies. A lot of research is funded by industry, which increases the probability of biases.

Divergent perspectives on the desirability of technological development give rise to divergent views on what are morally desirable form features of science in

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<sup>18</sup> Teule (2003), <http://www.stopumts.nl/pdf/folderwetenschap.pdf> (accessed april 11th, 2005)

<sup>19</sup> All reports of the Health Council on electromagnetic radiation (Health Council: 2001, 2002, 2003, 2006)

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this context. For the HC, only indications of harm that can be explained by widely accepted theories and that are reproduced warrant caution. For the opponents, any indication of harm is sufficient to take precautionary measures. The arguments put forward here are basically of a political nature because they touch upon question such as: Which interests should prevail in policies relating to technological developments? This issue will be taken up again in the discussion of the political debate. I will now consider the articulation constraint as it applies to the public debate.

### 6.2.2. Articulation constraint

The articulation constraint for public debates implies that arguments should not violate the form features of public identity as they are relevant to a particular debate. The arguments should furthermore also be coherent and intelligible and meaningful to the other participants in a debate. Only then do they have a normative appeal to other participants in the debate.

#### 6.2.2.1. Suspicion about motives

A substantial element of the various motivating narratives of the divergent actors is suspicion concerning the reasonableness of the mutual motives. The proponents feel that the opponents are motivated by irrational fear, whereas the opponents feel the proponents are biased by a misplaced technological optimism. Are these suspicions warranted, given the articulation constraint?

The opponents state that the view of the proponents may be distorted by their interest in the smooth enrolment of mobile phone technology. This distortion may lead them to be very selective in their assessment of scientific sources. To support their complaints about the bias of the authorities and the operators, the opponents draw parallels with the asbestos case where scientific evidence for adverse health effects was weak at the time, although available, and later even deliberately suppressed. In drawing this parallel they feel supported by large insurance companies who do not want to risk (again) covering liabilities for technologies that may turn out to have damaging effects (see Brauner: 1996).

Moreover, the Dutch government, along with other European governments, has received large sums of money, about 3 billion euros in the Netherlands, for UMTS frequencies by auctioning them to the providers in combination with the obligation to have the network up and running in four years. Indications of adverse health effects would problematise the position of the authorities in

relation to the providers. The government appears to have a genuine conflict of interest. In the view of the opponents, the government has disqualified itself as an able institution for balancing interests by committing to the economic development of mobile phone technology.

In contrast, the authorities and the mobile phone providers feel that the opponents are guided by unsubstantiated fears, which mainly arises out of ignorance or prejudice. The authorities and the providers feel that opponents only look at a limited number of inconclusive studies that point to possible harmful effects, whereas there is a large body of scientific evidence that appears to exclude the possibility of harmful effects. Their (irrational) fear has made them biased towards the available information. To illustrate this point, the fear of radiation is compared to the old fear of electricity. People used to be afraid of electricity, but when they had had time to adjust to its use, that fear subsided, the argument goes. Mobile phone technology evolves a bit faster, so it is understandable that people react in a more intense way (see Burgess: 2004, ch.3).

Additionally, scientists who side with the opponents camp are considered to be mainly motivated by self-promotion. Fuelling the opponents with a critical scientific standpoint lends these scientists an aura of the 'people's champion'. For scientists who have been otherwise marginalized, such a reputation might restore their social status.

The suspicions of the opponents are based on historical examples of companies suppressing information about the adverse health effects of their products, such as asbestos, tobacco and pharmaceutical companies. In some cases, governments appear complicit by putting economic interests before public health concerns. This narrative is one in which companies and some governments are guided by monetary interests, rather than the well-being of the general population.

Such narratives have some credibility as they can be illustrated with proven historical examples. However, whether they are applicable to the parties in this particular debate is questionable. There is no necessary link between historical examples and the contemporary positions in this debate. It is not an essential quality of lay audiences to fear new technologies, nor is it an indispensable quality of governments and companies to put money before public health. The opponents, may, in so far as they are laypeople, not regard themselves as particularly fearsome of new technologies simply because they are not

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technological experts even though they are perceived as such by the authorities and mobile companies. Likewise, the mobile phone companies may not regard themselves as the money-craving, relentless institutions the opponents portray them to be. The scientists who support the opponents will also not look upon themselves as vain self-promoters.

However, as was the case with the free-riders in the vaccination debate, sometimes an identity should be understood differently than the actor articulates that identity. This may have ramifications for the evaluations of a specific claim. I will now consider whether the narratives the actors recount of each other in this debate have any normative appeal within the public debate.

### 6.2.2.2. Respect for form features of identity

Respect for the form features of identity is a requirement of the articulation constraint in the public debate. Given the various form features of the relevant identities in this debate: To what extent are the suspicions the various actors raise against each other a reason to demand an altered attitude of accused actors? Form features are those aspects of an identity that are socially determined or theoretically derived and hence not open to individual interpretation. Possibly a party is mistaken about the form features of its identity and the associated rights and obligations. Should an individual (party) sometimes accept the narrative that others present of her identity, and if so, under what conditions?

In public debates, parties should have a chance to reject versions of their identity which are not their own (see Laden: 2001, ch.6). However, if an identity is incoherent or unintelligible to others, then this identity may be rejected by others and interpreted in a way that is coherent or intelligible (see chapter 5, section 3.1.2). Likewise, particular qualities may be ascribed to an individual (party) that are derived from a form feature of the identity of that individual (party). In such a case the individual has no ground to deny being characterized by that particular quality. It may for instance be claimed that one of the form features of the government, in most modern, western societies, is that it should find a tenable balance between public health concerns and economic interests. Indeed, a government representative of the Dutch department of housing, spatial planning and the environment from the directorate chemicals, waste, and radiation protection described the responsibility of the government as balancing out different interests, different points of view and taking a decision about those.

Relevant interests may be said to be public health, access to new technological developments, economic welfare and public anxiety.

This balancing of interests is a form feature of governments. It is a moral requirement on the behavior of governments. It is not a legal or constitutional quality of a government. If a government fails to find a tenable balance between public health and economic interests, it would cease to be government in a moral sense, but not necessarily in a legal or constitutional sense because that would require some additional actions such as the official resignation of the cabinet.

The above described form feature of government does not prescribe any distinct course of action. A balance between different interests could imply various courses of actions. An appeal to the above mentioned moral form feature of government does not necessarily give precedence to one of the narratives presented here. The narrative of the opponents about the motivations of a government should be allowed within the debate: it can be considered intelligible and meaningful, but it does not hold any normative force, i.e. it does not change the way the motives of the government have to be understood. The narrative the government puts forward does not lose any credibility, aside maybe for some particular participants in this debate. The Dutch government does what can be expected of a government, considering the form features of government: namely to find a balance between the divergent interests within a society. Whether the Dutch government has struck the right balance can in this case not be determined with reference to the form features of the relevant identities in the public debate. This question will return in the political debate.

With regard to the opponents: they appear to be lacking a coherent identity characterized by form features. All kinds of professions are represented in this group, as well as various levels of education. Therefore, it is problematic to ascribe a single identity to this group. The main common denominator is resistance to mobile phone technology. Such a resistance does not offer an identity with distinct form features. The narrative that depicts the opponents as ignorant and fearful is allowed within the debate as it is intelligible and meaningful, but it does not invalidate the way the opponents portray themselves, i.e. this narrative cannot be imposed on them.

An aspect of the identity of mobile phone companies that is relevant to this debate may be that they are expected not to let their particular interests prevail above public health. However, that this is an obligation of companies is not

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disputed by any of the parties. The disagreement is rather about whether public health is at stake at all.

The government is balancing public health against economic development, providers are seeking to maintain their economic position, the opponents are worried about adverse health effects. The question whether these motivations have indeed corrupted the positions of the participants in the debate, remains unanswered. The narratives are allowed within the public debate, but they may be rejected by the other participants, they do not necessarily lend a particular perspective a greater moral appeal within the debate than any other.

### 6.3. The political dispute

#### 6.3.1. The arguments

The political debate concerns the question: What kind of actions should be undertaken given the present circumstances of uncertainty about the risks involved and who should be responsible for these actions? Although there is relatively little scientific indication of possible harm, such indications might arise with new research under new criteria of harm. What does this imply for political action? Different actors have different ideas about this. The question is which of these ideas are most compelling given the value of respect for autonomy. First the different possible solutions to this debate as well as their supporting arguments as put forward by the participants in this debate will be described. Secondly, these actions will be assessed according to the articulation constraint.

##### 6.3.1.1. Precautionary measures

A possible political decision would be the implementation of precautionary measures, by imposing stricter safety norms than are currently in place. This would probably result in different design specifications for the mobile phone technology network. If the intensity of the radiation is lowered, then more antenna need to be placed to get adequate coverage. However, this might raise objections of a different kind, namely aesthetic. Other negative effects include additional costs for providers and for users, as coverage may be less consistent and possibly limited to designated areas.

The most relevant actor for taking political measures is the government. However, for the government, there is not enough reason at present to take precautionary measures that could possibly hamper economic development. The government mainly refuses to take such measures because they think the indications of harm are not sufficient. Additionally, taking precautionary measures might actually increase public anxiety instead of fostering trust in the governmental ability to deal adequately with the problem.

“It turns out in practice that field strengths are 20 times as low as the ICNIRP20-numbers. We could adjust the norms. One could wonder however, whether that does indeed foster trust. One needs a basis for such decisions. The norms we have now are based on scientific information. We have got a story to back up the norm, so to say, but one can also, as has happened in Italy or in Greece, take a different norm, but one has to motivate that (...) one has to have an explanation. Just saying something will not foster trust.”<sup>21</sup>

This concern about precaution in relation to trust is supported by recent research in this area, from which it has emerged that precautionary measures actually decrease trust in authorities in relation to EM-fields (see Wiedeman & Schultz: 2005)

A representative of a large Dutch operator of UMTS-technology likewise does not see any need for precautionary measures because a lack of reasonable scientific indications of physical harm makes it very hard to take precautionary measures:

“If it was proven, that that thing was unsafe, then we would have a very big problem. Then we should instantly modify or adapt the whole network, but at least we would know what to do. Now we don't know at all what we could do. Is diminishing the field strength something? The reason? Is that what causes people's complaints? Nobody has got that proof.”<sup>22</sup>

The opponents, to the contrary, feel that precautionary measures are warranted given the available evidence. According to them, the safety norms should be considerably lowered. They invoke comparisons with the safety norms in, for

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<sup>20</sup> ICNIRP is the abbreviation of International Commission on Non-Ionizing Radiation Protection who give out guidelines for radiation protection.

<sup>21</sup> Interview with representative of the Dutch department of housing, spatial planning and the environment, 8 April 2005

<sup>22</sup> interview with a representative of a large Dutch operator of UMTS-technology, 9 December 2005



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instance, Belgium, which are about 30 times as low as in the Netherlands, and New-Zealand where they are about 400 times as low as in the Netherlands. Such precautionary measures might imply that the design of the mobile telephone network would have to be adapted. The costs associated with this amendment do not, according to the opponents, outweigh the potential damage to public health.

### 6.3.1.2. Individual choice

A political course the government follows in the current situation is to allow people to make their own decisions about the acceptability of mobile phone technology. As the representative of the government specifically states, to a certain extent citizens are expected to take their own responsibility for particular decisions. People should decide for themselves whether they like to use mobile phones, whether they want to provide their children with mobile phones and whether they agree to have antenna placed on their roofs. However, the choice whether to buy a phone or not, is not considered a sufficient option for choice by the opponents. The purchase of a phone does not influence the siting of telephone antenna or the establishment of the safety norms, which is what the opponents are really after.

The consent procedures that are now part of the process of installing antenna allow individuals some room for autonomous decision making. The consent procedures as they currently take place in the Netherlands involve a written notification of the planned installation of an antenna, some information on possible health effects, as well as a request to return a form on which one's preference regarding the placement of the antenna can be revealed. If people have any concerns about telephone antenna, they can voice these concerns by refusing to have an antenna mounted on their rooftop. By implementing this procedure, the government hopes to avoid the situation that people feel powerless against the enrolment of a new technology by big corporations.

The opponents however, do not perceive the consent procedures designed by the government to be sufficient to respect their freedom of choice and sense of responsibility. They claim that the consent procedures are flawed for various reasons. The consent forms only allow for one voice per household, for instance, and people who do not hand in the forms are automatically considered to be in favor of placing the antenna. Furthermore, in the consent procedure as it is designed at present, there is no obligation to ask for renewed permission from occupants when a GSM antenna is adapted to a UMTS antenna. The

governmental representative acknowledged that the rules for the procedure are a bit vague on this issue, and it has recognized that it might be necessary to make renewed permission mandatory. Other options for individual choice may be envisionable, but these are the ones that have been brought forward and discussed in the Dutch debate so far.

### 6.3.1.3. □ Additional research

Another possible measure is to influence the dispute on the uncertainty about risks through initiating additional research, additional research would imply spending tax money which could have been spent otherwise. It implies utilizing scarce resources for a specific goal. Is this goal indeed worth spending money on and whose money should it be?

Most parties state additional research in general would be desirable, for diverging reasons. Dr Zwamborn, a professor in the field of electromagnetic radiation and a member of the Dutch standing committee on Radiation Protection, very strongly stressed the need for such additional research. The activities of the government so far are insufficient, he thinks:

“Well, I think one of the actions they [the government, LA] should have undertaken, is to act a bit more vigorously. If only they had put up additional research in a limited way, then they could have told the people: we are taking this seriously. We even take this so seriously that we want to have more research on it. What they are doing now is creating a breeding ground for conspiracy theories.”

Zwamborn thinks that additional research is warranted, if only to show that the government is willing to do something. The opponents also feel that more research should be undertaken to follow up on research that indicates the possible existence of harm. As Teule puts it:

“Concerning this research we asked the Dutch Health Council: Why don't you repeat this research? Why does everybody has to make up their own research? Repeat something for once. Everybody is all the time stressing that one study isn't a research, but nobody ever repeats anything.”

All parties see the government as the prime responsible actor in this respect. In October 2003 a report was issued by the Dutch institute for public health and the environment (RIVM), called “Nuchter omgaan met risico's” (Coping rationally with risks) which advised the government to invest in research in this

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issue. This advice stimulated parliament to pressure the government to take action.

A representative of a large Dutch operator of mobile digital communication feels that the prime responsibility for initiating research lies with the government, partly because he thinks it is very difficult to determine what should be investigated. Since the operators already paid a lot of money for the UMTS-frequencies, he would rather that the government invested that money in research. The governmental representative however, thinks this is a rather unconvincing position because the industry bears its own responsibility in this. So, according to the government, industry should take its responsibility for the effects of its products and this is indeed already the case, since industry is instigating research in different locations, if not in the Netherlands then in some other European country, alongside to the efforts of governments.

The governmental representative pointed out that the Dutch government is willing to invest in research. In this way it can show that the possible risks attached to EMR are taken seriously. According to the governmental representative, a lot of research is being done, either funded by the Dutch government or through European bodies. Furthermore there are plans to start up a research fund shared by the government and industry. The research would have to be conducted by independent researchers so there would be no suspicion of an unwarranted conflict of interests.

The actors involved agree additional research is necessary and that the prime responsibility for initiating this should be with the government and industry. Both government and industry recognize their responsibilities for making sure mobile digital communication is not causing adverse health effects. However, the various actors involved in this debate still do not agree on the amount of research required and the criteria under which this research should be conducted. It is therefore questionable how effective additional research will prove in moving the debate on.

New results from one Swiss study funded by the Dutch government emerged in 2006. This study reported no adverse health effects (see Regel *et al.*: 2006). Authorities and specifically the secretary of state of the ministry of housing, spatial planning and the environment at that time, claimed this result as conclusive for the debate and urged city councils to reopen their borders for new antenna. However, the opponents did not at all accept this result as conclusive,

mainly because the Swiss researchers had stated that no conclusion about the health effects of EM-fields could be derived from their results.

The results of another study that emerged in 2006 indicate some slight adverse health effects. As mentioned before, the INTERPHONE study found weak indications of a relation between cancer and EM-fields. This result has not been taken as conclusive by either of the parties but rather has been understood to support the need for further research.

### 6.3.2. Evaluation of the actions

How should these proposals be evaluated given the divergent arguments of the actors involved? The values that are relevant for this evaluation are the form features of the articulation constraint in the political context: non-malificence, justice, equality, and autonomy, because of their quality of overridingness, they hold a moral appeal to all participants in the political debate over other considerations. I will discuss these values in turn by considering their role in the evaluation of the arguments in this debate.

#### 6.3.2.1. □ Non-malificence:

Non-malificence implies that any harm to others should be avoided as much as possible. This can be interpreted as a strong motivation for precautionary measures in this case. The government however thinks that there is not enough evidence to take precautionary measures. This opinion is based on the advice of the HC. The operators align themselves on this point of view. The opponents instead plead for rigorous precautionary measures such as substantially lowering the safety norms.

The moral conflict related to this value can be explained as a conflict between avoiding of type 1-errors as opposed to avoiding type 2-errors. Type 1-errors refer to acceptance of a false positive; type-2-errors refer to avoidance of a false negative. Avoiding type 1-errors is part of conducting good science. However, when it comes to risk assessment, there are convincing ethical reason to focus on the avoidance of type-2-errors.<sup>23</sup> When dealing with risks, the less desirable outcome may not be to take something to be true which is not, but to disregard a potential danger.

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<sup>23</sup> Cranor 1990, Wandall 2004

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The avoidance of type-2-errors can be interpreted as a form of the Precautionary Principle. This principle dictates that lack of conclusive scientific evidence should not be taken as a reason not to take precautionary measures. However, whether it is a sufficient reason to take precautionary measures, is in most contexts a matter of intense dispute, for instance because precautionary measures might undermine other interests in society.

The opponents of mobile phone technology, although they do not formulate it as such, put their finger on the clash between sound science and morally desirable risk assessment. In their perspective, all indications and explanations for the existence of risks ought to be taken seriously, not just those that are based on conclusive evidence. If the government considers public health to be a top priority, it would strive to avoid type-2-errors more than type-I errors. Non-maleficence would then imply that possible risks ought to be avoided as much as possible. However, there are reasons related to the values of justice and equality that indicate the desirability of a different course of action.

### 6.3.2.2. Equality/justice

The value of equality requires that the different interests of the different parties are weighed equally, although it does not necessarily imply equal treatment. The value of justice requires that costs and benefits of a technology are distributed equally (see chapter 3, section 4.2.2). Reaching a just distribution is the task of the government. As the government representative stated, the government seeks to balance the different interests.

First let us consider the various interests. The interests of the opponents are clear. They want to radically alter the design specifications of the mobile phone network so that the intensity of the radiation is lowered. They also want some areas to be exempt from radiation entirely, both from GSM and from UMTS radiation, so that extremely sensitive people can take refuge there.

Accommodating these interests would have repercussions for other relevant actors. The operators would have to invest money in altering the mobile phone network. Consumers of mobile phones would have less coverage. They would only be able to use their phone in designated areas. Considering the rate of penetration of mobile phone technology at present, this would require a serious amendment of people's habits as most of us are quite accustomed to the use of mobile phones.

However, the opponents argue that the interests of consumers with regard to UMTS are not so pressing as to warrant the introduction of new risks, however ill-defined these risks may be. Communication may be important and sometimes even vital, but the gadgets that UMTS telephones offer are nothing more than distractions and entertainment, according to the opponents. Such technological developments are hardly worth the alleged risks associated with it. The benefits of UMTS technology are indeed not vital to a stable society. It is also questionable whether the development and enrolment of this technology is essential to the economic prosperity of the Netherlands. It seems that UMTS technology does not economically benefit society at large to any great extent, but mainly the producers of this technology, if it turns out to be a success. Such minimal benefits do not seem to legitimize the imposition of risks on highly sensitive people. Yet, the indications for adverse health effects are at present only minimal and weak. Such weak indications of risks provide little ground to hamper a technological development the benefits of which might be limited and vague at present, but which might turn out more beneficial in the future.

How to balance these different interests and perspectives in a just way? The concern of the opponents should be seriously considered. It appears unjust that highly sensitive people should carry all the burdens, while the other parties receive all the benefits: but since meeting the concerns of the opponents might hamper the interests of other groups, there is good reason not to grant the opponents their demands. If there was more certainty about adverse health effects resulting from antenna, the balance would change. Either it would be clear that it is everybody's interests to alter the intensity of the radiation because the evidence indicates that everybody will be affected. Or it would become clear, more than it is now, that a small group of highly sensitive people suffers disproportionately from electromagnetic radiation. However, even if more scientific evidence was available to support the health complaints of this group, that would not necessarily imply that the interests of the highly sensitive groups trump the interests of other groups, it merely implies that the balance between the different interests would shift.

Aside from possible health effects, another burden to consider is the anxiety the opponents experience about the enrolment of the network. This anxiety is very real and might exacerbate complaints about health. It might very well be the result of feelings of helplessness in the face of large technological developments. I think this anxiety should be taken seriously as a burden associated with this

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technological development, and possibly with many other technological developments. The anxiety of the opponents may very well result from a lack of influence on their environment, which may be regarded as an unjust situation. As Shrader-Frechette claims in her book on environmental justice, justice is as much about distribution of costs and benefits as it is about participation. “A principle of participative justice ensures that there are institutional and procedural norms that guarantee all people equal opportunity for consideration in decision making. Otherwise, victims of unequal opportunity are more likely to experience exploitation, marginalization, powerlessness and violence” (see Shrader-Frechette: 2002, 28). A principle of participative justice can act as an insurance that decisions are made in a way that respects the value of equality, i.e. in which all perspectives receive equal consideration. To meet the principle of participative justice, an open, inclusive decision procedure is required. How such a procedure should be designed in this case will be expounded in the section on freedom.

Another burden in this context is the burden of proof. In this case, those who have the resources to carry the burden of proof are also those who benefit most from the enrolment of the UMTS-network, namely the telephone providers. Considering the value of justice, those who benefit from a technological development should carry the associated burden, namely to provide the evidence on the safety or harm of a technological development that is required in a decision procedure on risk.

In conclusion, the desired course of action considering the values of justice and equality coincide with those demanded by the value of respect for autonomy. As explained in chapter 3, section 3.4.3, respect for autonomy requires that those with access to the required resources for providing evidence should carry the burden of proof. In this case, as in many other cases, those parties who benefit most from a technological development are often the ones with the best access to resources to provide evidence of harm. Furthermore, respect for autonomy also demands an open, inclusive decision procedure on the acceptability of risk in which all relevant actors can participate.

Considering the value of autonomy and justice, the actors in this case have accepted a desirable appointment of the burden of proof. The main remaining issue is that of participation. This issue will be considered extensively in the next section. Further research that results from the extended participation of

laypeople, may also impact upon considerations related to a just division of burdens.

### 6.3.2.3. □ Freedom

The government thinks that the consent procedures as they are installed at present in the Netherlands are an adequate way to ensure the freedom of individuals. Additionally, individuals can decide for themselves whether they want to buy a mobile phone. The operators basically share this point of view.

As argued before, the option to buy or not to buy an individual telephone should not be considered as an adequate way of guaranteeing freedom with regard to the risks discussed here. Additionally, aside from practical matters mentioned before, some more fundamental concerns can be raised against the consent procedures. These consent-procedures reflect a typically downstream inclusion of laypeople (cf. Wynne: 2002; Bijker: 2004). At the end of the line, people can assent or dissent to a development that is already finished. At this stage a technology has already gained a certain momentum that may make it look as an inevitable fact of life which leaves the individual few options for influence or even the incentive to try and influence that technology, whereas such options should possibly be available and indeed are theoretically available. Such options are certainly desired by the opponents. They have repeatedly voiced their preferences about the design specifications of the network several times.

The consent procedures as they are designed cannot be considered adequate because they shy away from the more fundamental issues relating to design specifications and whether sufficient research has been done to assume the safety of the network. It can be questioned whether the consent that is given through these procedures can be considered sufficient. The premises on which participation is shaped are in this case not shared by the different parties involved. It is as such not true participation. Concern about health is for instance not supposed to be a reason for dissent, because the government and the operators think there is no reason for concern for health.

It is furthermore presupposed that a decision procedure by majority voting is the right course of action to follow in this specific case. As such, the question as to whether this technology outweighs the objections a minority might raise against it has already been answered in favor of the technology.

Additional research may be the most feasible course of action to really address the concerns of the opponents. Participation of laypeople in the



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establishment of criteria for proof of risk is desirable to ensure freedom to influence the decision on the acceptability of mobile phone technology. Aiming to carry out additional research allows the freedom of the opponents to be respected while not jeopardizing the freedom of others who see less reason for concern at present. The criteria for evidence of risk for the opponents can be considered autonomous in the light of the demands of the reality constraint.

Setting up research which specifically takes into account these criteria seems an appealing option to restore trust and do justice to the concerns of the opponents. Such research obviously needs to take into account the criteria set by the HC for sound science. An agreement should be reached beforehand about how the results should be interpreted, i.e.: when they should be understood as indicating risks or when they should be understood as indicating safety and each party must show it is committed to the results. Of course, the arguments brought forward in the debate leading to the design of the experiment, ought to respect the demands of the reality constraint.<sup>24</sup>

Such a measure may influence the current debate in a way that does not violate any of the fundamental values of political decision making. Since the criteria for evidence of risk for additional research might lead to new indications of risk, the money would not be spent idly, which would harm the interests of other people. It is a collective interest to make sure that a technology is safe enough to use. The research the Dutch minister of the department of housing, spatial planning and the environment has issued in the mean time has not been designed in collaboration with the opponents.

Setting up additional research in collaboration with all actors is in line with the principles of equality and justice. Opening up decision procedure by allowing the opponents influence on the criteria for evidence of harm is a form of participative justice because each participant is granted equal access to the scientific material that informs the political decision with regard to the acceptability of the risks associated with mobile phone technology.

This course of action is furthermore in line with respect for autonomy, since it puts the burden of proof on the government and the providers. These parties

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<sup>24</sup> In the period between the initial study and analysis of this case and the writing of this chapter, the HC has issued new advice for further research which appears to take the concerns of the opponents into account. Although societal anxiety is mentioned as an important reason to undertake such research, there is no explicit reference of the concerns of the opponents. As such, they may still feel marginalised and therefore still not accept the outcomes of the new research.

are the ones most suitable to provide additional evidence. This division of burden of proof is in accordance with respect for autonomy. As explained in chapter 4, autonomy is closely linked to identity. Identity provides individuals with a moral framework on which they base their decisions. Identity, which comprises personal development and employment, likewise provides the individual with skills and resources to evaluate particular issues. In this case, the opponents have neither the skills nor the resources to provide additional evidence but their claims about the acceptability of the risks at scrutiny are tenable. These claims therefore provide reasons for other parties in the debate to act. The other parties in this debate, the providers and the government, have the resources and can mobilize the skills to provide additional evidence. Considering the value of respect for autonomy, they have an obligation towards the opponents of UMTS technology to provide this additional evidence.

A concern in relation to financing additional research is that it might also spark suspicion, specifically with those individuals who might have been concerned about, but are not actively opposed to, UMTS technology. If the government sees reasons for further investigation then there might be a good reason to worry about adverse health effects. However, such worries do not necessarily undermine the freedom of these individuals, nor is it incompatible with any of the other values.

### 6.4. Conclusion

The debate on the acceptability of technological risks associated with mobile phone technology is characterized by two opposing positions: those claiming that the risks are negligible and those claiming that the risks warrant a radically altered telephone network. The concept of narrative autonomy indicates a possibly course of action to move this debate forward that is in line with respect for autonomy.

First, both positions could be considered autonomous considering the articulation constraint as well as the reality constraint in the public debate. Therefore, considering the value of respect for autonomy, both positions should be taken seriously when arriving at political decisions on how to move forward with this debate.

Two interesting insights emerged from the application of the articulation and the reality constraint in the public debate. Firstly, a form feature of scientific

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practice, the conservative standard of proof, was put up for debate. The conservative standard of proof contrasts with a precautionary approach: when dealing with risks, the less desirable outcome may not be to take something to be true which is not, but to disregard a potential danger. Whether a conservative standard of proof is desirable in a specific context ultimately is a political issue. In this context, the conservative standard of proof was eventually considered justified considering the values of equality and justice.

Second, the narratives of the actors involved in the public debate consist for a large part of descriptions of the identity and motivations of the other actors. Claims are made that actors do not respect the form features of their own identity: i.e. that they behave in a way that is unacceptable given their identity and the related rights and obligations. However, in this case, the actors to which such corrupted motives are ascribed are not obliged to accept this description of their motives. The form features of the relevant identities do not invalidate the way the actors describe their own motivation, but neither can the description that other parties gave of their behavior be rejected on the ground of the form features of the relevant identities. Although all narratives live up to the articulation constraint, none of them can be imposed on other actors or acquired a special status within the debate.

From the political debate, three options for action emerged: precautionary measures, reliance on individual choice and additional research. The option of taking precautionary measures is desirable considering the value of non-maleficence, but not with regard to the value of equality and justice. Whether precaution is warranted may have to be decided by considering the result of additional research. Considering the values of equality and (participative) justice, this research should be designed in collaboration with all relevant stakeholders. The value of freedom demands a similar approach in this case. Options for individual choice are desirable with regard to the value of freedom, but the way the options are designed in this context is insufficient. Individuals should have the option to influence the design of research into the effects of electromagnetic radiation, to be really free to influence the decision concerning the acceptability of the risks involved. The burden of proof to provide this evidence should be appointed to the operators and the government, since these parties benefit most from this technological development and have access to the required resources. This is in line with the values of respect for autonomy and of justice.

# 7 Conclusion & Discussion

This chapter is intended to bring together the findings of the case-studies to evaluate the applicability of the concept of narrative autonomy to decision procedures on technological risks. I will first compare the three case-studies on their respective qualities. So far, I have drawn conclusions per case. The salient differences between them shed an interesting light on the concept of narrative autonomy. This comparison allows me to wrap up the conclusions to this dissertation. After that, I will briefly discuss some objections to narrative autonomy and how I think those objections could be dealt with. Lastly, I will indicate some directions for possible further research.

## 7.1. Recapitulating narrative autonomy

How successful has the endeavour been to arrive at recommendations for decision procedures on the acceptability of risks in which respect for autonomy is paramount? Has the concept of narrative autonomy proved useful to this end? As claimed in chapter 3, requirements for useful concepts of autonomy in this context are:

- (1) it should offer a basis to accommodate diversity
- (2) it should incorporate the social embeddedness of individuals
- (3) it should offer a basis to put constraints on arguments put forward in decision procedures on technological risks

All three requirements are incorporated into the notion of narrative autonomy. According to this notion, identity is central to autonomy. Identity offers a moral framework that guides the individual in decision making. Identity is narratively constructed. Social and cultural narratives offer a frame of reference from which individual narratives are formed. Within this frame of reference, a wide diversity of narratives is possible, each reflecting the distinct, unique identity of individuals, embedded in their social environment. As such the first two requirements are met by the concept of narrative autonomy.

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The articulation constraint and the reality constraint make up the contours within which identity supporting narratives should fit. These constraints fulfill the third requirement as mentioned above. They apply to the social and cultural background of the participants since this background offers individuals the resources to be autonomous. The articulation constraints consist of requirements of coherence and intelligibility of narratives as well as respect for the form features of identity. The reality constraint demands that narratives are compatible with the form features of science. The form features are those aspects of identity or social practices that are not open to individual interpretation; they are socially determined and/or theoretically derived. Form features support a morally desirable stability within a society and hence are worthy of respect by everyone. They may be questioned and eventually altered, but the burden of proof in such a case is on the person seeking to alter the form features. In contrast, content features of identities and social practices are those aspects that are open to individual interpretation.

### 7.2. Evaluation of the case-studies

In this section I will evaluate the applicability of the requirements of respect for narrative autonomy to actual decision procedures on the acceptability of technological risks, based on the results from the case studies. These requirements are: flexibility in criteria for evidence of harm, burden of proof appointed according to capacity and arguments put forward in public and political debates should meet the articulation and the reality constraint.

I will not explicitly evaluate the first requirement concerning the flexibility of criteria of evidence of harm. This is a relatively straightforward requirement the applicability of which is commonly unproblematic. Any problems that might arise with this requirement will be considered with regard to the reality constraint, which denotes the limits of the flexibility with regard to the criteria for evidence of harm. I will devote most attention to the constraints since these have been most explicitly applied to the cases.

#### 7.2.1. Burden of proof

The requirement to appoint the burden of proof to the party who is most capable to provide this proof follows from the recognition of the importance of identity for autonomy. In the three cases, the burden of proof was either irrelevant in

that particular situation, appointed to other parties than those most capable of providing the required proof, or appointed in line with this requirement but for other reasons.

In the vaccination case, only the claim of the group with the holistic worldview might become stronger because of additional evidence. Any additional evidence produced would only impact upon the debate if it would be in support of the view of this group. However, the criteria for evidence of harm this particular group puts forward do not meet the reality constraint and are hence unsuitable as a basis to collect additional evidence, regardless of the question concerning which party should provide that evidence. In the GMO case the burden of proof rested with the parties seeking to protect themselves against a possible harm, which are not always the parties most capable of providing the required evidence. According to the requirement derived from the concept of narrative autonomy the burden of proof should rest with the parties that have access to the necessary resources which are usually the producers of GMO's.

In the UMTS case the burden of proof did practically rest with the parties most capable of providing this proof. In this case the burden of proof was appointed to the government and the operators of mobile phone technology because of considerations of trustworthiness and accountability. The government wanted to show that it took the concerns of citizens seriously and hence that it was trustworthy. The operators wanted to make sure that they did not disseminate harmful technologies, which would make them liable for damages. Since the requirement as based on the concept of narrative autonomy was met in the UMTS case, albeit for different reasons than respect for (narrative) autonomy, the findings from this case indicate that this requirement concerning the burden of proof can be applied.

However, in this specific case, the criteria for evidence of harm were not determined in deliberation with all the relevant actors, which should have been done to respect the autonomy of all the parties involved. Therefore, the way the different tasks were organized in this case is not entirely in line with respect for narrative autonomy, although the outcome would have been the same if the recommendations derived from narrative autonomy had been followed. This implies that at least there appear to be no practical obstacles to appoint the burden of proof while taking the issue of identity into account, however, there may be other obstacles.

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A question that has not been answered by the findings from the case studies is whether it is feasible to expect parties to provide evidence in support of a perspective on a particular risk that clashes with their particular interests. Often the producers of a specific technology are those with sufficient resources to provide the required evidence. However, if this evidence is such that it would establish the harmfulness of their products, they may be reluctant to invest in producing such evidence. This reluctance might affect the reliability of the evidence. This is an issue that is worth investigating. I will come back to this in the section on further research.

### 7.2.2. The articulation constraint in the public debate

In the public debate the articulation constraint requires that claims made should be intelligible and coherent, and that they should reflect respect for the form features of relevant identities. As shown in the vaccination case, the first requirement can be meaningfully applied. In this case, the members of one group do not present their claim as being a free-riding claim, which makes them unintelligible and hence their claim needs not to be respected as an autonomous claim. Their claim is only recognizable as an autonomously made claim if it is presented as free-riding behaviour, because only then this claim is intelligible. If it would indeed be presented as a free-riding claim, the claim would become problematic in the political debate. A free-riding claim is not morally acceptable considering the values that constitute the articulation constraint in the political debate, such as equality.

The usefulness of the second requirement demanding respect for relevant form features is more ambiguous, for two reasons. One, as emerged from both the vaccination and the UMTS case, the identity of the divergent actors cannot always be captured in form features. This is true for the rather heterogeneous group of opponents in the UMTS case but also for a more homogeneous group such as the religiously motivated in the vaccination case. Therefore, the identity of the various actors does not offer an irrefutable basis for normative appeals to other parties. Since these specific identities are not characterized by form features that deserve respect from everyone in a society, people who do not share that identity cannot be obliged to acknowledge the moral demands that follow from this specific identity.

Two, even if an identity can be captured in form features, as is possible in the UMTS case for actors such as the government, these form features do not necessarily have a clear discriminatory function within such a debate. The form features allow for a diversity of sometimes conflicting perspectives. Divergent claims about how the government ought to behave appear to be equally viable with regard to the form features of governments. Neither the claim that the government should hold public health to be of paramount importance in this case, nor the claim that the government should hold economic interests to be of paramount importance in this case can be dismissed on the ground of the form features. The form features denote the central obligations of the government, but how these obligations are fulfilled in a specific context such as the debate on the acceptability of the risks associated with UMTS technology remains a matter of individual interpretation. In this case this interpretation differed per actor in a way that cannot be resolved with reference to the form features. Therefore each of these claims was allowed within the debate, but neither of these claims was considered to have an overriding value when considering the form features of identity in the public debate. The discriminatory function of the second requirement of the articulation constraint in public debates has not been shown in these cases, but the possibility remains that there may be cases in which this second requirement is useful.

### **7.2.3. The articulation constraint in the political debate**

In the political debate the articulation constraint requires that decisions made should comply with the form features of citizenship, which consist of the quality of overridingness and four basic values. For modern, western nation states I have defined these as: freedom, equality, justice and non-malificence. It turns out that both in an international and in a national context it is possible to identify values that constitute the articulation constraint for the political debate, however, the way these values are applied remains distinctly context-dependent.

Both the national and the international context are typified by diversity. This is self-evident for the international context, and although I argued in chapter 4 that each nation state can be attributed a specific identity that does not imply that nation states consist of homogeneous populations. Nation states often consists of a wide diversity of different individual identities. Nonetheless, for each of



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these contexts some basic shared values can be identified that should be considered the form features of (international) citizenship.

At least, for the national context I have assumed this to be possible because it seems that every society needs a set of basic shared values to maintain a morally desirable social stability. I think this assumption can be considered correct given that the constitutions of western nations reflect a recognizable set of basic values. I have introduced my own perspective on which values constitute the form features of citizenship in western democracies, which I think is in accordance with the underlying values of the constitutions of most western democracies. In a national context most individuals do not actively endorse the constitutive values of the nation to which they belong, for instance by becoming members. This contrasts with the actors in the international context: the nation states who actively sign up to international treaties. However, individuals in a national context may be expected to accept the form features of citizenship as applicable to their political environment if they do not actively challenge these form features.

In the international context of the GMO case, the form features of international citizenship can be seen as exemplified in the values underlying the policies of both the UN and the WTO. In this context, the relevant actors have actively endorsed the policies of the relevant organisations by choosing to become members, and in the case of the Cartagena Protocol on Biosafety, by intentionally subscribing to the UN's policies with regard to GMOs. A set of shared basic values can be identified despite the many differences between the international actors.

This does not imply that the different actors in either context will always understand the form features of (international) citizenship similarly. Differences between the moral outlooks of the various actors subscribing to a similar a set of values may come forward more prominently once the values are applied in a specific context. For instance, many nation states are members of both the UN and the WTO while these organizations have opposing policies in some areas. Either this indicates a lack of consistency in the choices made by these nation states or it indicates that the values underlying the respective policies are in conflict only once they are operationalized. This latter option may very well be the case for the particular context of the GMO case. The values that led to the opposing policies in this case are respect for external autonomy versus respect for internal autonomy. As Isaiah Berlin has remarked, the notions of negative

and positive freedom, which are comparable to external and internal autonomy, are not necessarily conflicting concepts. It is even sometimes difficult to separate the two. Historically they have given rise to conflicting political systems (see Berlin 2002b) and the policies of the UN and the WTO might be exemplary for such conflicting political systems.

Differences in application of values will arise most prominently in an international context. Although nation states have actively endorsed the form features of international citizenship, in contrast with actors in a national context, it can be expected that these form features will give rise to debates more often than the form features of citizenship in a national context. In a national context, the form features can be more narrowly defined, leaving less room for varying interpretations, because the diversity within one nation is generally less than the diversity between nations. The form features of citizenship on an international level should be more generally and loosely defined to appeal to as many different actors as possible and to gain their active endorsement of the values. It is possible to formulate universal values that appeal to people on a global scale, but their actual practical implications will emerge most clearly once they are applied in a specific context.

Practical implications of values depend on the context, this is also true for the way values are balanced against each other. As is indicated by the vaccination case, the articulation constraint does not necessarily lead to absolute moral judgements. The claims of the free-riding group can be deemed inappropriate because of the form features of citizenship, but how the claim of the religiously motivated should be treated remains unresolved. How the conflicting demands of the relevant values are balanced is a matter that needs to be decided upon deliberatively between the divergent actors within this specific context. However, it can still be concluded that the values do offer a manageable framework to assess the various policy options available in a case. In the UMTS case for instance, the form features of citizenship present an indication of a desirable approach to the decision on the acceptability of the risks associated with mobile phone technology. Considering the four values, some of the proposed actions could be dismissed as inappropriate. The only action that was found to be acceptable was to allow the opponents influence on determining the criteria for evidence of harm, whereby the resources to provide this evidence would have to come from the operators and the government.

### 7.2.4. Reality constraint

The reality constraint is meant to allow for a diversity of risk representations, while the quality of these representations is constrained by the demand for compliance with basic scientific norms, or in my terminology: the form features of scientific practice. Two major conclusions concerning the applicability of this constraint come forward from a comparison of the case-studies.

One, the form features of science do not necessarily offer a strong demarcation line between viable and non viable representations of risk. Two, one of the epistemic values: the conservative standard of proof, should not be applied in all decision procedures on technological risks.

With regard to the first point about demarcation: some representations of risk might violate all scientific epistemic values, while other representations will comply with all scientific epistemic values, but there may be many representations of risk which are somewhere in between. Whether they are acceptable or not is a matter of degree. The claims of the group with a holistic worldview in the vaccination-case were dismissed as failing to adhere to the reality constraint while the arguments of the opponents in the UMTS case were considered to meet the reality constraint. In both cases, scientific support for the respective positions is minimal compared to support for the opposing positions. Both groups rely on theories that are outside the generally accepted body of knowledge. So what is the difference?

Evidence in support of the view of the opponents of UMTS technology is minimal, but exists in such quantities as to warrant further research. Additionally, the views of the opponents have elements of theories that are outside the scope of mainstream accepted hypotheses, but which are not entirely unlikely. These theories have not been generally accepted, but they appear to be in principle, compatible with major accepted theories. It might for instance very well be conceivable that adverse health effects related to electromagnetic radiation will emerge only after an extended period of exposure.

In contrast, the evidence in support for the view of the group with a holistic world view is extremely limited. In the vaccination case there are almost no scientific publications in support of their view. Additionally, this group stretches the notion of scientific evidence to include publications that represent only a point of view and which have not been peer-reviewed and are not reproducible. Aside from that, their perspective on health and disease is not merely a bit exotic; it is to a large extent incompatible with mainstream accepted theories.

However, even this view contains some elements that are compatible with the relevant body of scientific knowledge, such as the claim that the incidence of detrimental diseases dwindled because of improved sanitary conditions. Concluding, although the difference between these positions might be seen as a matter of degree, it is still a relevant matter of degree. As such, the reality constraint can be considered a useful tool for distinguishing between viable and non-viable representations of risk.

The second point that emerges from the case studies, most notably from the GMO and UMTS cases, is that a conservative standard of proof, which is usually considered to be of scientific, epistemic value, is questionable as a necessary scientific epistemic value in decision procedures on risk. This standard implies that if the scientific evidence is inconclusive, a hypothesis regarding the existence of a specific phenomenon or causal relations is rejected. To stay on the safe side, a hypothesis is only accepted if there is a substantial amount of evidence to support it. This prevents the false acceptance of hypotheses.

This epistemic value is questioned in both the GMO and the UMTS case, but interestingly enough, it is questioned for different reasons. In the GMO case I argue that the Precautionary Principle, which can be understood as refutation of the conservative standard of proof, accommodates internal autonomy better. In the UMTS case the conservative standard of proof is questioned because of concerns about public health.

The main difference between these cases concerns the division of risks and benefits. The GMO case is not about divergent interests within a society, but about the diverging interests of relatively separate actors, namely of individual nation states. In contrast, the UMTS case deals with a conflict over the acceptability of risks within a society. In the UMTS case, any decision with regard to the acceptability of the risks involved will affect several actors whether they consent to the risks or not.

The decision whether to accept or reject the risks associated with GMOs is a matter for a particular nation state alone, because it alone has the burdens of the risks involved.<sup>1</sup> If a nation state accepts the (alleged) risks associated with GMOs, it does not imply that other parties will also have to bear that risk. The external autonomy of other actors is not threatened by the risks associated with GMOs. Therefore, when deciding on the acceptability of risks associated with GMOs, *the*

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<sup>1</sup> Unless it turns out that GMOs can cross pollinate over great distances, something which until now has not been scientifically established.

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*perspectives on that risk* of other actors such as other nation states and biotechnology companies are morally irrelevant, although they may be informative or politically relevant. However, the external autonomy of other actors is threatened by a decision to ban GMOs from that nation state, because then other actors will not be able to trade these GMOs. Hence, *the economic interests* of other parties are morally relevant. Therefore, any decision relating to the acceptability of GMOs has to be scientifically tenable, so that it can be justified to other parties.

The most important consideration for embracing a precautionary approach in this context is to allow nation states to make their own decision regarding the acceptability of GMOs and hence to respect their specific perspective on the risks involved. The Precautionary Principle allows parties to take measures against a risk even if the evidence provided is inconclusive. Conclusive evidence is evidence beyond reasonable doubt, implying that it is acceptable to all parties involved. However, in this case, respect for internal autonomy requires that the evidence provided should put forward specifically the perspective of the nation state. It need not be compatible with the perspectives of other actors. It need only be of such a scientific quality that other actors can accept the reasonableness of the representation of the risks, although they might disagree with the content of the representation.

In the UMTS case the applicability of a conservative standard of proof is debated by the actors involved. In this case the argument in favour of taking a precautionary approach is related to the protection of public health. In this respect, it is more important to avoid false negatives than to avoid false positives. Put differently: when dealing with risks, the less desirable outcome may not be mistakenly to take something to be true which is not, but to disregard a potential danger. Hence, any reasonable indication for a potential risk should be taken seriously. However, as becomes clear in the UMTS case, interests other than safety concerns might be harmed by such an approach. If a strict precautionary approach is followed, society in general may be denied the possible benefits of UMTS technology. Consideration of the various interests associated with a technological development within a society may therefore lead to discarding the precautionary approach.

In this case, deciding whether to take a precautionary approach requires the balancing of different interests. The actors claiming that a precautionary approach is necessary support this claim with reference to a general interest that

is shared by everyone within Dutch society, namely public health. However, whether public health is indeed at stake in this debate depends on which perception of the risks involved can be considered most tenable.

Respect for internal autonomy can in this context not immediately lead to a precautionary approach because the perspectives of several parties on a specific risk have to be considered simultaneously. The UMTS-case represents a clash between two divergent perceptions of the risks associated with a similar technology. In the UMTS case respect for the internal autonomy of the various parties requires respect for their perspective on the risks involved. This has been operationalised as the requirement that the opponents can influence the criteria for evidence of harm that determine the design of further research in this area.

### **7.2.5. Comparison with other approaches**

The findings from the case studies indicate some aspects on which narrative autonomy improves on concepts of autonomy as brought forward by Mill, the feminists and Kant. Narrative autonomy is more symmetrical concerning respect for internal and external autonomy than Mill's concept of autonomy. Narrative autonomy offers a more specific framework to evaluate arguments in public and political debates than feminist concepts of autonomy. Narrative autonomy offers more specific moral guidance than Kant's categorical imperative.

With regard to a Millian understanding of autonomy: narrative autonomy incorporates respect for internal autonomy understood as the aspects of autonomy that are internal to the agent. Such aspects include a framework for reflection and deliberation over resources. As shown in the GMO case, an approach based on a Millian concept of autonomy in which respect for external autonomy is of paramount importance, exemplified in the WTO policies, is problematic with regard to respect for internal autonomy. The WTO approach disregards specific cultural outlooks typical for nation states and difference in capacities to provide scientific evidence between nation states. Respect for narrative autonomy leads to respect for internal autonomy because it acknowledges the importance of identity. Therefore it requires that the burden of proof is appointed according to capacity and that, in the GMO case, the divergent perspectives of the nation states are respected by dropping the epistemic value of a conservative burden of proof. In this way, the differences between the actors in their moral frameworks of reference and in their capacity to scientifically

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support their arguments will not impact on their opportunities to influence decisions on the acceptability of technological risks as is now the case under WTO policies.

With regard to the feminist's concept of autonomy: narrative autonomy clearly distinguishes between aspects of identity and of social practices that are open to individual interpretation and those that are not. According to most feminist authors, an individual is autonomous because of, and through the relationships, she maintains. Relationships give meaning and guidance to an individual's life. However, conceiving of autonomy as the product of contingent circumstantial influences makes autonomy an empty concept, which leaves little room to distinguish between autonomous and non-autonomous judgments and actions. The distinction between content and form features of identity allows critical assessment of narratives and arguments. In the vaccination case for instance, I imagine that a general feminist approach has little to offer to assess the divergent claims of the three groups critically. Each group makes a claim which is sincerely motivated by a concern for their children. Each group as such acts upon the moral incentive provided by the care relationship with its children. As such, each claim might be perceived as autonomous considering that relationships make us autonomous individuals. However, I think we want to approach the divergent claims more critically than that, as each claim has consequences for the health of other individuals. Narrative autonomy does offer a framework to approach these claims more critically.

With regard to Kant's concept of autonomy: narrative autonomy offers a clear set of basic values on which to base decisions concerning the acceptability of technological risks. The categorical imperative, which demands that autonomous judgements are universalizable, offers a more general approach to distinguish between relevant arguments in the political debate. Such an approach would have helped somewhat to assess the divergent claims in the vaccination case as the free-riders claim is incompatible with the categorical imperative. However, with regard to the other claims and also with regard to the divergent perspectives in the UMTS case it would have been less effective in distinguishing the moral weight of the various claims. It seems that the claims of the religiously motivated and those with a holistic worldview in the vaccination case are in principle universalizable: given their moral frameworks and their perceptions of the risks involved, they could want it to be a law that everybody rejects vaccination. The same goes for the two opposing sides in the UMTS case: both claims with regard

to the acceptability of risk are universalizable: either dismantling mobile phone technology or the unrestricted enrolment of it are universalizable given the moral frameworks and the perceptions on the risks involved of the various relevant actors. Narrative autonomy allows a more refined assessment of claims made within decision procedures on the acceptability of technological risks by incorporating the moral meaningfulness of the context through the form features of identity and of scientific practice, which is desirable given the impact of these decisions on other individuals.

### **7.3. Implications for decision procedures on the acceptability of technological risks**

What general impact does the concept of narrative autonomy have on decision procedures on technological risks as we know them? One, participation in these decision procedures will be more open because of the recommendations based on narrative autonomy. Two, respect for autonomy implies respect for identity which has implications for how actors should be addressed. Three, explaining the basic values used for political decision making provides moral guidance and makes clear what individuals within a society can expect and demand from each other when it comes to political decisions dealing with the acceptability of risks.

With regard to the first impact, the openness of participation: the concept of narrative autonomy gives rise to clear directions to design decision procedures on the acceptability of technological risks in which respect for individual autonomy is of paramount importance. Narrative autonomy provides a framework to consider mutual responsibilities. It explicates what we can demand from each other on the basis of the values and narratives that we share. These shared values and narratives are important because they make us free.

The availability of a framework to respect autonomy will have implications for the openness of participation in such processes. The concept of narrative autonomy demands recognition of the importance of identity for autonomy. Identity implies diversity in perspectives on risk, which leads to the demand for flexibility in criteria for evidence of harm. Identity implies diversity in capacities, skills and resources for providing the required evidence to support a claim about a specific risk. This leads to the demand for the burden of proof being appointed according to capacity. Lastly, identity is narratively constructed within the framework of surrounding social practices and cultural narratives, which leads to



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the demand that arguments put forward in public and political debates should meet the articulation and the reality constraint.

Flexibility in criteria for evidence of harm will ensure that a wider diversity of representations of risks will be taken into account in decision procedures on the acceptability of risk. These criteria are based on the assumptions underlying the perceptions of risk. These assumptions arise out of the specific worldview of actors. This worldview is related to the identity of actors.

The requirement to appoint the burden of proof to the party that is most capable of providing this proof evens out the power disbalance between these parties with access to resources opposed to the parties without these resources. If (groups of) individuals do not have access to resources to support their perspective on a specific risk with scientific evidence, this does not necessarily imply that this evidence can not or should not be produced. If the criteria for evidence of harm are within the reality constraint and the evidence is relevant to the decision on the acceptability of risk, then another party with sufficient resources should provide this evidence. In many cases the actors that benefit financially from a specific technological development also have the resources to provide scientific evidence regarding its safety, namely the producers of technological artefacts. It appears reasonable to appoint these actors the burden of proof. Of course, the evidence provided should live up to criteria for evidence that is acceptable to all relevant parties. In the current situation, producers of technology are often legally required to provide evidence regarding the safety of their products, but they are not required to provide evidence according to criteria of evidence of actors who question the safety of their products. In my view, the producers should provide evidence according to these criteria as long as they comply with the reality constraint.

With regard to the constraints the most important gain lies in the clear articulation of the requirements on arguments put forward in decision procedures on the acceptability of technological risks. The constraints do not necessarily lead to any revolutionary insights on what is required of arguments in debates on technological risks nor should they. They are the result of respected social practices and institutionalized cultural narratives that are considered to be worthwhile in the context of decision procedures on the acceptability of technological risks. However, to clearly articulate these requirements might be revolutionary as for now, they are mainly implicit. Articulating what is required of arguments such that they ought to have an

appeal for other participants can make these procedures more open, since then, paradoxically, the extent of ones participation is actually less determined by personal identity. The influence one has within a debate depends less on whether one is a layperson or an expert, but foremost on whether the arguments one puts forward meet the constraints. The constraints reflect the acknowledgement that identity is important for autonomy without putting identity before autonomy. The possibility one has to influence decisions on the acceptability of technological risks depends on whether one's arguments meet the Constraints which are derived from recognition that identity is socially constructed and that it is constitutive for autonomy. The possibility one has to influence decisions on the acceptability of technological risks does not depend on what identity one has.

This brings us to the second impact of the concept of narrative autonomy on decision procedures concerning the acceptability of technological risks. In another way the various identities of actors involved in debates may have greater impact within the debate than they have now. Although, as emerged from the case studies, claims stemming from the particular identities of the actors involved do not necessarily give rise to morally compelling arguments for other participants, identities should nonetheless be respected as the constitutive source of norms and values for individuals. If identity is of paramount importance for autonomy, which I claim it is, respect for autonomy implies respect for identity.

Therefore it is important within any public debate to address parties on aspects of their identity that they themselves subscribe to. For instance in the UMTS case, the opponents to UMTS technology are addressed as an irrational, fearsome lot, while this group understands itself as rational and critical. I propose to approach this group as rational and critical so that they feel compelled to behave as such. For instance, as I propose in chapter 6, this can be realized by inviting them to influence the criteria for evidence of harm. They can and should accept the results of research that has been designed according to pre-agreed criteria for evidence of harm.

With regard to the third impact, concerning the values in the political debate: the main benefit of my approach lies in the articulation of the basic shared values: freedom, equality, justice and non-malificence and their quality of overridingness. These values are not revolutionary, nor should they be expected to be as they are assumed to be those values that are generally accepted within a

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society. However, to position them clearly in decision procedures regarding the acceptability of technological risks is new and makes these procedures more democratic. A political decision regarding the acceptability of a risk has to comply with basic shared values, which make up the articulation constraint in political debates. Decision makers can be held accountable on this aspect of their decision.

### 7.4. Objections: conservatism and relativism

Some objections spring to mind when considering narrative autonomy and its impact on decision procedures on the acceptability of technological risks. I will discuss two main lines of objection: first the objection of conservatism followed by the objection of relativism.

#### 7.4.1. Conservatism

The charge of conservatism basically says that the concept of narrative autonomy gives unwarranted precedence to those social institutions and moral outlooks that dominate a society, possibly to the extent of excluding or oppressing dissident perspectives. Many feminist authors have claimed, and shown, that science is for instance an institution that can not be considered to be neutral with regard to the divergent interests within society. As the feminist critique of science goes, in scientific practice the perspectives of women have traditionally been marginalized in many disciplines (see Longino: 1994).

Additionally, with regard to the articulation constraint, the charge would imply that positioning form features of identity that should be respected by all members within a society supports existing practices and hence those parties who benefit from these practices. This is especially true for the form features of citizenship. Dictating central values that should be respected by all participants within a society risks the exclusion of dissident perspectives, such as those of immigrants or political radicals. Such an approach stifles openness within a society, which in turn undermines individual autonomy.

My initial reply to both these elements of the charge of conservatism is that respect for narrative autonomy is especially meant to preserve openness within a society. This openness is meant to enhance and support diversity within society. With regard to the objection that science should not necessarily be considered a neutral procedure for the production of knowledge: that is something I

acknowledge. As I have repeatedly stressed in this research, scientific risk assessment that is compatible with respect for autonomy should be open to input from a wide range of different, relevant actors. However, I claim that the epistemic values that underlie scientific practice, the form features, can be considered to be neutral with regard to the various interests within a society. They have proven their worth as guidelines for scientific practice. They render science the socially robust enterprise that it is, because the results these epistemic values produce, can be justified to all involved actors. These actors can be expected to cherish these values and can be called upon to do so. I claim that problems with exclusion and lack of democracy relate predominantly to the content features of science, i.e. with the way a risk is represented. One specific way of perceiving a risk may be dominant at the expense of other perspectives on that risks, which are equally viable considering the epistemic values of science.

It might be argued that even the basic scientific epistemic values reflect an oppressive attitude. The value of simplicity might for instance lead to simplistic explanations for phenomena that have a very complex causal history. Such simplistic explanations are likely to reproduce dominant perceptions within a society, thereby excluding minority perspectives and the role of traditionally marginalized groups such as women. My reply is that as far as epistemic values might reflect an oppressive attitude they should be adapted. I have argued for this myself in relation to the decision procedure on the acceptability of GMOs. Although some form features may be incompatible with respect for autonomy in a specific context, I think that in general they are unproblematic and that it is desirable to grant form features a special status, which may be questioned only under specific circumstances. Feminists mostly accept the basic epistemic values, although some would add one or two (see Longino: 1994).

With regard to the objection concerning the form features of identity my reply would point out that form features are not immutable. They can be altered if need be, but only because of long winding social changes within a society, or because of reasons offered by a party seeking such changes that are convincing enough to all other parties within a society. However, such conditions for altering form features may be deemed too demanding to guarantee openness. If the reasons to justify alterations to form features need to be justified to other parties within a society, or if society itself needs to change, this sets high barriers to anyone with a dissident perspective on the form features.

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I want strongly to stress again the difference between form and content features, which is relevant also with regard to identities in general, and in particular to the identity of citizen. Content features of identity are explicitly open to individual interpretation. The way each of us practices parenthood, friendship, partnership and professional identity is up to individual interpretation. Existing social and cultural narratives may provide inspiration with regard to the content features of identity, but they do not determine these content features.

This is different for the form features of identity. As I explained in this research, I think it is defensible to lend these form features a special status in that they may only be questioned under special circumstances. These form features have this special status because they are essential for the (moral) stability of a society. As such, they are also essential for the autonomy and self-understanding of individuals within that society. An unstable society with diffuse frameworks of reference does not offer a basis for individuals to create meaningful self-understanding. If the points of reference for such an identity are constantly in flux, the individual has little to relate to for constructing his individual identity. Therefore, identifying form features which are not susceptible to individual interpretation does not undermine individual autonomy, but enhances it.

Form features are not immutable products of age-old traditions and social practices, although they may be. Form features are those aspects of identity that are valuable to all members of society, not just to a specific, privileged group. Moreover, identifying such form features can work to the advantage of previously disadvantaged groups. It gives them an argument to question the authority of dominant groups. Is the authority of such groups warranted given their identity? Does this identity consist of form features that should elicit respect from other members of a society? The possibility that form features of identity are such that they advantage specific groups in society is limited by the form features of citizenship. Inequalities between different groups in a society are a matter of political decision making. Inequalities are incompatible with the form features of citizenship and can therefore be expected to be removed.

#### 7.4.2. Relativism

A different objection that might be raised against narrative autonomy is the charge of relativism. To situate individual autonomy explicitly within a cultural and social context to the extent that being an autonomous individual depends on the adherence of one's narratives to constraints whose meaning derives from that context, invites relativism. If context provides the main source of value, then: How should we deal with a context that we consider to be morally dubious such as in a nation state where values such as justice and equality are not respected? Does this imply that for individuals situated in such a context these values do not apply? And if autonomy is shaped by context: Is there any overarching standard for autonomous agency or can we never criticize the narrative identity and the associated claims of individuals from a different cultural background?

It may be difficult to assess the narratives of individuals from different cultural backgrounds. Different cultural contexts will give rise to different form features of identity. They may apply different social categories and structure their narratives in different ways. This would imply that the articulation constraint in the public debate is useless, because the requirements of intelligibility and respect for the form features of relevant identity do not apply between individuals from different cultural backgrounds. Moreover, individuals from different cultural backgrounds may hold different values of paramount importance. As such, the articulation constraint in the political debate likewise becomes useless as there is no common moral ground to give meaning to this constraint.

With regard to the requirements of intelligibility and respect for relevant form features, I assume that these can be applied across different cultures, although less strictly than within a specific cultural context. I assume that even between different cultures enough similarities exist to understand each other's narratives and conceptions of identity. Cultures may differ, for instance, in the way families are structured, but they will be similar in that in most cultures, family is a cherished entity. Different cultures have different traditions, which can be incomprehensible to others; there can still be a mutual understanding between cultures that some traditions are highly valued. I assume that the articulation constraint can be meaningfully applied in public debates even between individuals from different cultural backgrounds. Whether my assumptions are correct is material for further research.

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I think the same goes for the articulation constraint in political debates as I explained in my discussion of this constraint in this chapter. Some basic moral values can be defined that appeal to actors on a global scale as is shown by the subscription of many nation states to bodies of global governance such as the UN and the WTO. Even if a nation state does not explicitly embrace these basic moral values, this does not imply that the people within such a state do not embrace such values. People may suffer from an oppressive, abusive regime. The values may still have a global appeal. That we are generally able to identify the situations in which people suffer from oppressive regimes, supports the assumption that some moral values are meaningful across different cultural contexts.

As I have also indicated above, moral values might be operationalised differently in different cultural contexts. This might cause disagreement between parties from different cultural backgrounds, but such disagreement about what respect for basic moral values includes exactly may also arise between members of a similar cultural background. I do not think that such disagreement undermines the claim that it is possible to define form features of global citizenship.

Similarly, even though some concepts, such as family, are shared between different cultures, this does not imply that all concepts are shared between different cultures. Some practices and traditions from some cultures will be totally alien to other cultures and traditions. Again, I think such differences will arise even between members from similar cultures. We should not expect nor strive for homogeneous frames of references. What is more important, given the variability in narratives, cultural concepts and understanding of the requirements of respect for basic moral values is continuous communication. Given the wide range of different perspectives and moral outlooks, it is always, and constantly necessary, to try and see each other's point of view, to be open to dissident perspectives and search for the common moral ground from which to proceed in debates on issues of a moral nature. I think this openness is captured in the value of equality as it demands that all perspectives initially receive equal consideration.

### 7.5. Directions for further research

The concept of narrative autonomy offers substantial material for further research. Some directions that come to mind are the distinction between respect for external and internal autonomy with regard to decision procedures on risk, the role of experts, explication of the appointment of the burden of proof and how the concept of narrative autonomy might be applied to others areas. I will briefly consider these directions in turn.

#### 7.5.1. Internal/external autonomy

I have positioned narrative identity as related to the internal aspect of autonomy. Internal autonomy refers to those factors that contribute to individual autonomy that are internal to the agent, such as mental capacities and emotional stability. Narrative identity provides a framework of reference on which an individual can base her decisions. It offers the individual tools for reflection. The ability to critically reflect on one's decision is an aspect of internal autonomy. Furthermore, the notion of identity also comprises one's skills and social resources that follow from education and professional and social development. These aspects of one's identity are also internal to the agent, as they are the result of the choices an individual makes and they impact on mental processes and emotional well-being.

However, in some respects narrative identity might be understood as linked to external autonomy. External autonomy refers to those factors that contribute to individual autonomy that are external to the agent. If a specific narrative is for instance not tolerated within a society, this might limit the autonomy of an individual. He may be unable to construct his narrative identity in a way that helps him to be autonomous because the narrative that suits him is not available to him. He may be at a loss to describe his own life and his motivations and may thus feel alienated from himself because of the attitudes present in his social environment that are external to him.

However, such a situation might also be thought of as a lack of internal autonomy. Internally autonomous individuals might be expected to possess enough creativity to concoct their own narratives, even if society does not explicitly acknowledge these narratives. New narratives will be constructed continuously, partly from existing narratives, partly from original elements, even if the individual proves creative enough to construct a narrative that suits her,



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her autonomy might still be hindered by a society that suppresses such narratives. If the individual is unable to express her narrative identity in public, if she only receives negative feedback on her identity, then she may start doubting her narrative or feel pressured to change this narrative. Again, such problems might also be thought of as relating to internal autonomy. An internally autonomous individual might be expected to withstand societal pressure and to stand her ground. She may be expected to cherish her own personal narrative even if society does not support her.

I think these questions shed an interesting light on the traditional distinction between positive and negative freedom which resembles the distinction between internal and external autonomy. Although this distinction cannot always be strictly drawn, gaining a better understanding of the differences between these two concepts can prove useful to the development of the concept of narrative autonomy and for related areas such as political philosophy.

### 7.5.2. Role of experts and identity

Another issue that needs further research is the role of experts in decision procedures on the acceptability of technological risks. More specifically: What can be expected of experts and when can they be trusted by laypeople? It might be claimed that experts are only trustworthy if they respect the form features of their identity. But does the identity of experts consist of form features and if so, what are they?

There is a tendency to clearly define the values that should guide the behaviour of researchers at universities for instance. In 2006 the Association of Universities in the Netherlands set out a detailed description of such values. These values might be understood as the form features of the identity of university researchers, but possibly there are also other candidates for form features of the identity of scientific expert.

This issue becomes ever more pressing in the light of the increasing commercialisation of university research. Do the form features of the identity of university researchers allow for commercial research? This issue is also worth investigating with regard to experts who serve in regulatory bodies or government offices. What exactly is their role? What responsibilities do they have to the public? To what extent is their role socially determined? To what extent is the fulfilment of their tasks up to individual interpretation? To what extent are

government officials individually responsible and to what extent is the government responsible for their conduct?

### 7.5.3. Burden of proof

I have formulated the appointment of the burden of proof according to capacities as a requirement on decision procedures regarding the acceptability of technological risks. It might be interesting to investigate how this requirement works in practice. And also: To what extent is it already common in current decision procedures on the acceptability of technological risks and for what reasons? Does it indeed shift the power balance? Does a difference in control over resources always imply a difference in the capacity to influence decisions concerning the acceptability of risks?

An important consideration in this respect is whether parties can be expected to invest resources in evidence that might clash with their own interests. Often the parties with access to the resources to provide the required evidence are the producers of the technology in question. These producers may be reluctant to investigate the possibility of a causal link between an adverse health effect and their own products, according to the suggestions put forward by parties critical of that technology. In the long run it is also in the interests of the producers that all harmful effects related to their products are identified. Marketing harmful products does little for a company's image, or its profits, especially if it has to pay out on damage claims. Identifying all possible harms gives producers the opportunity to amend the design of a product and to show that they are reliable producers.

Up to a certain extent, producers of technologies are already responsible for the research regarding the safety of their products. Products have to meet standards set by regulatory institutions, however, in debates concerning the acceptability of technological risks these standards are often questioned. The safety standards may be the result of a procedure in which only a limited group of stakeholders was represented. If individuals who were not part of this procedure question these standards, producers might be required to provide additional evidence regarding the safety of their products. In this respect this requirement exceeds the current responsibilities of producers of technological artefacts.

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Appointing the burden of proof according to capacity is intended as a measure to shift the power balance between different groups in society. However, it may be questioned as to what extent this unequal power balance can really be resolved. A related question is just how problematic this unequal power balance really is. In a modern society, characterized by specialization, capacities for supporting a specific claim with regard to the perceived risks associated with a particular technology will always differ substantially between various parties. The level of technological and scientific literacy impacts on these capacities. Appointing the burden of proof to the party most capable to provide this proof will only partly remedy differences in arguing capacity. If these differences are the result of specialisation within society, and if we think that specialisation is generally a good thing, then possibly we should accept the ensuing differences, up to a certain point.

### 7.5.4. Immigration and cultural integration

An interesting direction for further research is to apply the concept of narrative autonomy to a completely different area. Such an application will contribute substantively to the explication of the concept. What does narrative autonomy, for instance, have to offer for discussions concerning cultural integration and immigration? In this area, the concept of identity and social embeddedness can be problematized in very interesting ways.

When immigrants settle in their new nation state, should they be expected immediately to embrace the form features of citizenship of that nation state, including the aspect of overridingness? I think much can be said for such an approach. Settling into a new country implies becoming a member of the political community of that country. If the immigrant takes on the identity of citizen of their new nation state, then other individuals who are already members of that political community should address the immigrant as a full member of that community. In political debates, the identity of the immigrant is then foremost a citizen of the new nation state, other aspects of her identity, such as immigrant, or representative of a relatively unknown religion, are secondary. In public debates, these other aspects of the identity of an immigrant may play a more dominant role.

The form feature of overridingness of citizenship may have consequences for such issues as dual citizenship. If the form features of the identity as citizen of

each country are incompatible, then possibly the immigrant will have to choose between these two aspects of her identity.

Another issue is how the narratives of immigrants will impact on the social and cultural narratives that dominate in their new nation states. The various cultural narratives of immigrants will probably remain a minority perspective, but they can, and possibly should, impact the existing narratives in such a way that the narratives of the immigrants is accommodated. It remains to be seen to what extent such an impact is indeed desirable considering the autonomy of the various individuals involved. What some cultures regard as oppressive practices with regard to the treatment of women may be considered as a token of respect or personal freedom in other cultures. Can, and should, such diverging narratives be reconciled? Possibly the autonomy of some individuals is best supported if some oppressive narratives disappear altogether: But who decides which is the oppressive narrative? If a cultural narrative disappears, even if it is considered oppressive, it might possibly undermine the narrative autonomy of the individual.

To conclude, the main contribution the concept of narrative autonomy can make to any debate that raises questions related to autonomy is the realisation that human beings are not autonomous by themselves, they are autonomous because of and through the social and cultural context in which they live and develop. This context enables autonomy by offering structures of meaning and values. These structures offer freedom and a basis on which we can enjoy this freedom together with others. We are free because of the things we share.



# Bibliography

- Adams, John. (1995) *Risk, the policy implications of risk compensation and plural rationalities*: London: UCL Press.
- Airaksinen, T. (1994) Service and science in professional life. In *Ethics and the profession*, edited by R. Chadwick. Avebury: Aldershot.
- Anderson, L. (1999) *Genetic engineering, food and the environment. A brief guide*. Bristol: Green Books ltd.
- Ankum, S., Bakker, P., Bruch, N., Guinee, P., Janssen, I., Kantén, E.v., Martens, M., Prent, N., Sanen, G. & Schaper, T. (2001) Ziektes en vaccins nader bekeken. In *Laat je informeren over vaccineren*. Roosendaal: Nederlandse Vereniging voor Kritisch Prikken.
- Appiah, K.A. (2005) *The ethics of identity* Princeton: Princeton University Press
- Asselt, M, Mellors, J., Rijkens-Klomp, N., Greeuw, S.C.H. Molendijk, K.P.G., Beers, P.J., and van Notten, P. (2001) Building blocks for participation in integrated assessment: a review of participatory methods. Maastricht: International Centre for Integrative Studies.
- Asveld, L. (2005) That inaudible sound: public regulation, risks and mobile digital communication. In: *Proceedings of the sixth international conference of computer ethics: philosophical enquiry*, Enschede, The Netherlands, 17-19 July, 2005
- (2006) Informed consent in the fields of medical technological practice. *Techné* 10 (1): 18-34
- (2007) Autonomy and risk: criteria for international trade regimes. *Journal of Global Ethics* 3 (1):21-38.
- (2008a) Mass-vaccination programmes and narrative autonomy. *Bioethics* 22 (5): 245

## Respect for Autonomy and Technological Risks

- (2008b) Trust and criteria for proof of risk. The case of mobile phone technology in the Netherlands. In *The Ethics of Technological Risks* edited by L.Asveld & S.Roeser. London: Earthscan (forthcoming)
- Atkinson W, Wolfe C, Humiston S, Nelson R, eds. (2000) *Epidemiology and prevention of vaccine-preventable diseases (the pink book)* Atlanta: Centers for Disease Control and Prevention
- Baier, A. (1986) Trust and anti-trust. *Ethics* (96):231-60.
- Barber, B.R. (1984) *Strong democracy: participatory politics for a new age*. Berkely: University of California Press.
- (1989) Liberal Democracy and the costs of consent. In *Liberalism and the moral life*, edited by N. Rosenblum, L. Cambridge, MA: Harvard University Press.
- Basser, S. (1997) Anti-immunisation scarce: the inconvenient facts. *'The Skeptic' Journal* 17 (1). .
- Baumuller, H., Sogaard, K. & Apea, Y. (2006) Overview of the WTO biotech dispute and the interim ruling: international centre for trade and sustainable development. Available from: <http://www.trade-environment.org/output/theme/tewto/biotechcasebackground.pdf> [accessed January 14th, 2006]
- Beck, U. (1992) *Risk society: towards a new modernity*. Edited by M. Featherstone, *Theory, culture and society*. London: Sage Publications.
- Bennett, R. (2001) Informed consent and HIV: public health versus private lives. In *Informed consent in medical research*, edited by L. T. Doyal, J S. London: BMJ books.
- Bergin, L. A. (2002) Testimony, epistemic difference and privilege: how feminist epistemology can improve our understanding of the communication of knowledge. *Social Epistemology* 16 (3):197-213.

- Berlin, I. (2002a) John Stuart Mill and the ends of life. In *Liberty*, edited by H. Hardy. Oxford: Oxford University Press. Original edition, 1959.
- (2002b) Two concepts of liberty. In *Liberty*, edited by H. Hardy. Oxford: Oxford University Press. Original edition, 1958.
- Bijker, WE. (2004) Sustainable policy? A public debate about nature conservation in the Netherlands. *History and technology* 20 (4):371-391.
- Borst, P. (2006) Tolereren, corrigeren of royeren. *NRC Handelsblad*, december 2: 46.
- Brauner, C.(1996) *Electrosmog: a phantom risk*. Zurich: Swiss Re.
- Bridges. (2005) *GMO UPDATE: US-EU, CHINA, AFRICA*. IUCN 2003 Available from <http://www.ictsd.org/biores/03-08-25/story2.htm>. [accessed 14-04 2005].
- Brody, B. A. (2001) A historical introduction to the requirement of obtaining informed consent from research participants. In *Informed consent in medical research*, edited by L. T. Doyal, J S. London: BMJ Books.
- Broek, N v. d. (2003) Power Paradoxes and in Enforcement and Implementation of World Trade Organization Dispute Settlement: interdisciplinary Approaches and New Proposals. *Journal of World Trade* 37 (1):127-162.
- Brom, F.W.A. (2004) WTO, public reason and food. Public reasoning in the 'trade-conflict' on GM-food. *Ethical Theory and Moral Practice* 7:417-431.
- Brown, M.B. (2006) Survey article: citizens panels and the concept of representation. *Journal of Political Philosophy* 14 (2):203-225.
- Buchanan, A. (2004) Political liberalism and social epistemology. *Philosophy and Public Affairs* 32 (2):95-130.
- Burgess, A. (2004) *Cellular phones, public fears and a culture of precaution*. Cambridge: Cambridge University Press.



## Respect for Autonomy and Technological Risks

- Busby, H. (2004) Blood donation for genetic research: what can we learn from donors' narratives? In *Genetic databases: socio-ethical issues in the collection and use of DNA*, edited by R. C. Tutton, London: Routledge.
- Callahan, D. (2003) *What price better health*. Berkeley: University of California Press.
- Carter, I. (2007) *Positive and negative liberty*. Stanford University (2003) Available from <http://plato.stanford.edu/entries/liberty-positive-negative/>. [accessed 3 October 2007].
- Castells, Manuel. (2004) *The power of identity*. 2nd ed. 3 vols. Vol. 2, *The information age: economy, society and culture*. Malden: Blackwell Publishing.
- Chadwick, R. (2005) Professional ethics and the 'good' of science. *Interdisciplinary Science Review*. 30 (3): 247-256
- Christman, J. (1991) Liberalism and individual positive freedom. *Ethics* 101:343-359.
- (2004) Relational autonomy, liberal individualism, and the social constitution of selves. *Philosophical studies* 117 (1-2):143-164.
- (2005) Saving positive freedom. *Political Theory* 33 (1):79-88.
- Collingridge, D. (1980) *The social control of technology*. London: Pinter.
- Cornes, R & Sandler, T. (1996) *The theory of externalities, public goods and club goods*. 2nd ed. Cambridge: Cambridge University Press.
- Cowen, T. (2007) *Public goods and externalities* 2007 Available from <http://www.econlib.org/library/Enc/PublicGoodsandExternalities.html> [accessed 22 aug 2007].
- Cranor, C.F. (1990) Some moral issues in risk assessment. *Ethics* 101 : 123-143.

- (2005) Scientific inference in the laboratory and the law. *American Journal of Public Health* 95 (S1):S121-S128.
- Cvetkovich, C., Vlek, C. & Earle, C. T. (1989) Designing technological hazard programs: towards a model of risk-adaptive decision making. In *Social Decision Methodology for technological projects*, edited by C. C. Vlek. Dordrecht: Kluwer Academic Publishers.
- Daniels, N. (1979) Wide reflective equilibrium and theory acceptance in ethics. *Journal of Philosophy*:256-282.
- (1985) *Just Health Care*. Cambridge: Cambridge University Press.
- Dare, T. (1998) Mass immunisation programmes: some philosophical issues. *Bioethics* 12 (2):125-149.
- Davies, P, Chapman, S & Leask, J. (2002) Antivaccination activists on the world wide web. *Archives of disease in Childhood* 87:22-25.
- Dijk, B van. (2005) Spanning loopt op bij uitrol UMTS. *Financieel Dagblad*, 2.
- Douglas, M. & Wildavsky, A. (1982) *Risk and Culture: an essay on the selection on technical and environmental dangers*. Berkeley & Los Angeles: University of California Press.
- Dworkin, G. (1988) *The theory and practice of autonomy*. Edited by S. Shoemaker, *Cambridge studies in philosophy*. Cambridge: Cambridge University Press.
- Dworkin, R. (1977) *Taking rights seriously*. Cambridge: Harvard University Press.
- ETCGroup. (2003) The big down. Winnipeg: ETCGroup.
- Faden, R, & Beauchamp, Tl. (1986) *A history and theory of informed consent*. New York: Oxford University Press.

## Respect for Autonomy and Technological Risks

- Federal Office of Radiation Protection. (2005) Comments on the 'Naila Mobilfunkstudie' by the BFS: Federal Office of Radiation Protection.
- Feenberg. (1995) *Alternative modernity: the technical turn in philosophy and social theory*. Berkeley & Los Angeles: University of California Press
- Fischhoff, B., Lichtenstein, S., Slovic, P., Derby, S.L. & Keeney, R.L. (1981) *Acceptable risk*. New York: Cambridge University Press.
- Frankfurt, G. (1988) Freedom of the will and the concept of a person. In *The importance of what we care about*, edited by G. Frankfurt. Cambridge: Cambridge University Press.
- Friedlander, ER. (2001) Opposition to immunization: a pattern of deception. *Sci Rev Alt Med*. 5 (1):18-23.
- Friedman, M. (1962) *Capitalism and freedom*. Chicago: Chicago University Press.
- Gaus, G.F. (1996) *Justificatory liberalism*. Edited by D. R. Miller, A., *Oxford Political Theory*. Oxford: Oxford University Press.
- Gee, D & Stirling, A. (2003) Late Lessons from early warnings: improving science and governance under uncertainty and ignorance. In *Precaution, environmental science and preventive public policy*, edited by J. Tickner. Washington DC: Island Press.
- Gerdes, J. (2002) *Killing the messenger* Available from <http://www.globalexchange.org/countries/americas/mexico/biodiversity/232.html>. [Accessed 14 April 2006]
- Gibson, M, ed. (1985) *To breathe freely; risk, consent and air*. Totowa: Rowman & Allanheld.
- Giddens, A. (1990) *The consequences of modernity*. Stanford: Stanford University Press.

- Gordon, D. R., & Paci, E. (1997) Disclosure practices and cultural narratives: understanding concealment and silence around cancer in Tuscany, Italy. *Social Science & Medicine* 44 (10):1433-1452.
- Guillou, M. (2001) *The French Diet Embassy of France in the USA*, available at <http://www.ambafrance-us.org/atoz/diet.asp> [Accessed 10 January 2006]
- Gupta, A. (2000) Governing trade in genetically modified organisms: the Cartagena Protocol on Biosafety. *Environment* 42 (4):23-33.
- (2004) When global is local: Negotiating safe use of biotechnology. In *Earthly politics, worldly politics: local and global in environmental governance*, edited by M. L. Jasanoff, S. Cambridge: MIT Press.
- Haimes, E. & Whong-Barr, M. (2004) Levels and styles of participation in genetic databases: a case study of the North Cumbria Community Genetics Project. In *Genetic Databases: socio-ethical issues in the collection and use of DNA*, edited by R. C. Tutton, O. London: Routledge.
- Hansson, S.O. (1991) *The Burden of Proof in toxicology*. Stockholm: Kemikalieinspektionen.
- Hansson, Sven Ove. (2002) Philosophical Perspectives on risk. Chapter read at Research in Ethics and Engineering, April 25 2002, at Delft University of Technology.
- Hardell, L., Carlberg, M. & Mild, K.H. (2005) Case-control study of the association between the use of cellular and cordless telephones and malignant brain tumors diagnosed during (2000)-(2003) *Environmental Research* 100 (2): 232-241.
- (2006) Pooled analysis of two case-control studies on the use of cellular and cordless telephones and the risk of benign brain tumours diagnosed during 1997-(2003) *International journal of oncology* 28 (2):509-518.
- Harris, J & Wood, S. (2001) Rights and responsibilities of individuals participating in medical research. In *Informed Consent in medical research*, edited by L. T. Doyal, J S. London: bmj books.

## Respect for Autonomy and Technological Risks

- Hassanein, N. (2000) Democratizing agricultural knowledge through sustainable farming networks. In *Science, technology and democracy*, edited by D. L. Kleinmann. New York: State university of New York press.
- Have, H. ten & Lelie, A. (1998) Medical ethics research between theory and practice. *Theoretical medicine and Bioethics* (19):263-276.
- S.W. Hawkins. (1996) *A brief History of Time*, London: Bantam Press
- Health Council of the Netherlands 2001 Elektromagnetische velden: Jaarbericht 2001 Electromagnetic fields: Annual update (2001) The Hague: Health Council of the Netherlands, 2001; publication no.2001/14.
- Health Council of the Netherlands. (2002) Mobile telephones; an evaluation of health effects. The Hague: Health Council of the Netherlands publication no. 2002/01E.
- Health Council of the Netherlands. (2003) Health effects of exposure to radiofrequency electromagnetic fields: Recommendations for research. The Hague: Health Council of the Netherlands, 2003; publication no. 2003/03.
- Health Council of the Netherlands. (2006) Proposals for research into health effects of electromagnetic fields. The Hague: Health Council of the Netherlands; publication no. 2006/11E
- Held, D. (1995) *Democracy and the global order: from the modern state to cosmopolitan governance*. Cambridge: Polity Press.
- (1996) *Models of democracy*. 2nd ed. Stanford: Stanford University Press.
- Hett, A. (2004) Small matter, many unknowns. Zurich: Swiss Reinsurance company.
- Hollingworth, R.M., Taylor, S.L., Meade, B.J., Kimber, I., Bolger, M., Bjeldanes, L.F., Wallace, K. (2002) *The safety of genetically modified foods produced through biotechnology* Society for Toxicology, Available at

[http://www.toxicology.org/Information/GovernmentMedia/GM\\_Food.html](http://www.toxicology.org/Information/GovernmentMedia/GM_Food.html). [Accessed 10 January 2006]

- Hoven, J. v.d. (2005) E-democracy, E-contestation and the monitorial citizen. *Ethics and information technology* 7: 51-59
- ICNIRP. (1998) Guidelines for limiting exposure to time-varying electric, magnetic and electro-magnetic fields (up to 300 GHz). *Health Physics* 74 (4):494-522.
- Igumed. (2002) Freiburger Appell. Bad Sackingen, 9 october 2002
- Irwin, A & Wynne, B. (1996) Introduction. In *Misunderstanding science: the public reconstruction of science and technology*, edited by Irwin, A. & Wynne, B. Cambridge: Cambridge University Press
- Isaac, E.G. (2003) The WTO and the Cartagena Protocol: international policy coordination or conflict? *Current: agriculture, food & resource issues* (4):116-123.
- Isaac, E.G. & Kerr, W.A. (2003) Genetically modified organisms at the World Trade Organization: a harvest of trouble. *Journal of World Trade* 37 (6):1083-1095.
- Jasanoff, S. (1991) Acceptable evidence in a pluralistic society. In *Acceptable evidence*, edited by D. G. H. Mayo, R.D. Oxford: Oxford University Press.
- Jasanoff, S., Wynne, B., Grove-White, R., Busch, L., Winickhoff, D. (2004) Amicus Curiae Brief, Submitted to the dispute settlement panel of the World Trade Organization, in the case of: EC: Measures affecting the approval and marketing of biotech products.
- Kamler, H. (1994) *Identification and character*. New York: State university of New York Press.
- Kant, I. 1785/(1996) Grounding for the Metaphysics of Morals. In *Kant, Practical Philosophy*. Cambridge: Cambridge University Press.

## Respect for Autonomy and Technological Risks

Kaplan, L. (2000) Public participation in nuclear facility decisions: lessons from Hanford. In *Science, technology and democracy*, edited by D. L. Kleinmann. New York: State university of New York press.

Katoni, K. (2007) *Chapela & Quist: kernels of truth*. East Bay Express

2002 Available from <http://www.mindfully.org/GE/GE4/Chapela-Quist-Kernels-Of-Truth29may02.htm>. [Accessed 27 November 2007].

Kaye, J. (2004) Abandoning informed consent: the case of genetic research in population collections. In *Socio-ethical issues in the collection and use of DNA*, edited by R. C. Tutton, O. London: Routledge.

Kersting, W. (1992) Politics, Freedom and Order: Kant's political philosophy. In *Cambridge companion to Kant*, edited by P. Guyer. Cambridge: Cambridge University Press.

Kleinmann, D.L. (2000) Democratizations of science and technology. In *Science, Technology & Democracy*, edited by D. L. Kleinmann. New York: State university of New York press.

----, ed. (2000) *Science, technology and democracy*. Edited by S. R. Croissant, J., *SUNY series in Science, Technology and Democracy*. Albany: State University of New York Press.

Kluver, *et al.* (2000) Europta: European Participatory Technology Assessment. Copenhagen: The Danish Board of Technology.

Korfmacher, Carsten. (2006) *Personal Identity* 2006 [cited 22-08-2006]. Available from <http://www.iep.utm.edu/p/person-i.htm>.

Korsgaard, C. (1992) The sources of normativity. In *The Tanner Lectures on Human Values*. Cambridge.

Krimsky, S. (2003) *Science in the private interest: has the lure of profit corrupted biomedical research*. Lanham: Rowman & Littlefield publishers ltd.

Kwame, A.A. (2005) *The ethics of identity*. Princeton: Princeton University Press.

- Kweon, Y. & Kockelman, K. "Overall Injury Risk to Different Drivers: Combining Exposure, Frequency and Severity." *Accident Analysis and Prevention* 35, no. 4 (2003): 441-50.
- Kyle, W.S. (1992) Simian retroviruses: poliovaccin and the origin of aids. *The lancet* 339 (8793):600-601.
- Laden, A.S. (2001) *Reasonably Radical, deliberative liberalism and the politics of identity*. Ithaca: Cornell University Press.
- Lanctot, G. (1995) *The medical mafia: How to Get Out of It Alive and Take Back Our Health & Wealth*. Waterloo: Here's the key Inc.
- Leask, J & McIntyre, P. (2003) Public opponents of vaccination: a case-study. *Vaccine* (21):4700-4703.
- Lefler, D.E. & Gabler, H.C. (2004) The fatality and injury risk of light truck impacts with pedestrians in the United States. *Accident analysis and Prevention* 36 (2):295-304.
- Legemaate, J. (2001) Informed Consent. In *KNMG consult*, edited by KNMG. Utrecht: KNMG.
- Longino, H. (1994) In search of feminist epistemology. *Monist* 77:472-485.
- Martin, B., & Richards, Evelleen. (1995) Scientific knowledge, controversy, and public decision-making. In *Handbook of Science and Technology Studies*, edited by S. Jasanoff, Markle, G. E., Petersen, J. C., & Pinch, T. Newbury Park: Sage.
- Martin, M W & Schinzinger, R. (1983) *Ethics in Engineering*. New York: Mac Graw Hill.
- Meyer, D.T. (1989) *Self, society and personal choice*. New York: Colombia University Press.



## Respect for Autonomy and Technological Risks

- Mike, V. (1991) Understanding uncertainties in medical evidence: professional and medical responsibilities. In *Acceptable evidence*, edited by D. G. H. Mayo, R.D. Oxford: Oxford University Press.
- Mill, J.S. (1972) On liberty. In *Utilitarianism, On liberty, Considerations on representative government*, edited by H. B. Acton. London: J.M. Dent & Sons Ltd.
- Millstone, E., Brunner, E. & Mayer, S. (1999) Beyond 'substantial equivalence'. *Nature* 401:525-526.
- Moynihan, R., Heath, I., Henry, D. (2002) Selling sickness: the pharmaceutical industry and disease mongering. *BMJ* 324 (13 april 2002):886-91.
- Murphy, J. (2004) *Science and international trade agreements: the case of trade in GMO's*. Available from <http://www.genomicsforum.ac.uk/documents/pdf/TheCaseOfTradeInGMOs.pdf>. [Accessed 27 January 2006]
- Musschenga, A. W. (1999) Empirical science and ethical theory: the case of informed consent. In *Reasoning in ethics and law*, edited by A. W. S. Musschenga, W.J. v.d. Ashgate: Aldershot.
- (2005) Empirical Ethics, Context-sensitivity and contextualism. *The Journal of Medicine and Philosophy* 30 (5):467-490.
- Navarro, E.A. *et al.* (2003) The microwave syndrome: A preliminary study in Spain. *Electromagnetic biology and medicine* 22 (2-3):161-169.
- Neitzke, H-P. (2001) ECOLOG-study by order of the German T-Mobile refers to health risks. *press-release*.
- Nussbaum, M. (2000) *Women and human development: the capabilities approach*. Cambridge: Cambridge University Press.
- (2001) *Upheavals of thought*. Cambridge: Cambridge University Press.

- Odent, MR, Culpin E.E., Kimmel, T. (1994) Letter to the Editor. Pertussis vaccination and asthma: Is there a link? *JAMA* 1994; 272:592-3.
- O'Neill. (2002) *Autonomy and trust in bioethics*. Cambridge: Cambridge University Press.
- Pacini, S *et al.* (2002) Exposure to global system for mobile communication (GSM) cellular phone radiofrequency alters gene expression, proliferation, and morphology of human skin fibroblasts. *Oncology Research* 13 (1):19-24.
- Parfit, D. (1984) *Reasons and persons*. Oxford: Oxford University Press.
- Peter, F. (2004) Choice, consent and the legitimacy of market transactions. *Economics and Philosophy* 2004 (20):1-18.
- Plochg, T. & Staa, A.L. van. (2002) Vaccineren als dilemma: een verkennend onderzoek naar alternatieve risicoafwegingen van ouders. *TSG Tijdschrift voor gezondheidswetenschappen* 80 (1):27-34.
- Powerwatch. (2005) *Powerwatch news 2005* Available from [http://www.powerwatch.org.uk/news/20041222\\_reflex.asp#fore](http://www.powerwatch.org.uk/news/20041222_reflex.asp#fore). [Accessed 23 August 2005]
- Prent, N. (2000) Kinkhoestvaccinatie:we prikken onze kinderen lek! *Trouw*, 09-12-(2000)
- Prent, N. & Schaper, T. (2003) Twijfel groeit met kennis. In *Laat je informeren over vaccineren*. Roosendaal: Nederlandse vereniging voor kritisch prikken.
- Rawls, J. (1996) *Political liberalism*. New York: Colombia University Press.
- Regel, S.J. *et al.* (2006) UMTS base station-like exposure, well being and cognitive performance. *Environmental Health Perspectives* 114 (8):1270-1275.

## Respect for Autonomy and Technological Risks

- Ricoeur, P. (1991) Life in quest of narrative. In *On Paul Ricoeur*, edited by D. Wood. London: Routledge.
- Roeser, S. (2002) *Ethical intuitions and emotions: a philosophical study*. Amsterdam: Vrije Universiteit.
- (2006) The role of emotions in judging the moral acceptability of risks. *Safety Science* 44: 689-700
- Roeser, S. & Asveld, L. (2008) *Overview of the book* In *The Ethics of Technological Risks* edited by L.Asveld & S.Roeser. London: Earthscan (forthcoming)
- Sandel, M.J. (1984) The procedural republic and the unencumbered self. *Political Theory* 12 (1):81-96.
- Schnapper, D. (2002) *Citizenship and national identity in Europe* Nations and nationalism 8 (1): pp. 1-14
- Schechtman, M. (1996) *The constitution of selves*. Ithaca: Cornell University Press.
- Scheer, L. v.d. & Widdershoven, G. (2004) Integrated empirical ethics: loss of normativity? *Medicine, Health care and Philosophy* 7 (1):71-79.
- Scheibner, V. (1993) *100 Years of orthodox research shows that vaccines represent a medical assault on the immune system*. Santa Fe: New Atlantean Press.
- (1998) Comments on Japanese SIDS "rebuttal". *Vaccination Information Service*.
- Schermer, Maartje. (2001) *The different faces of autonomy, a study on patient autonomy in ethical theory and hospital practice*. Ridderkerk: Ridderprint B.V.
- Schneewind, J.B. (1992) Autonomy, obligation and virtue: an overview of Kant's moral philosophy. In *Cambridge companion to Kant*, edited by P. Guyer. Cambridge: Cambridge University Press.

- (1998) *The Invention of autonomy: a history of modern moral philosophy*. Cambridge: Cambridge University Press.
- Sclove, R. (2000) Town meetings on technology: consensus conferences as democratic participation. In *Science, technology and democracy*, edited by D. L. Kleinmann. Albany: State University of New York Press.
- Sclove, R.E. (1995) *Democracy & technology*. New York: The Guilford Press.
- Sen, A. (1985) *Commodities and capabilities*. Amsterdam: Elsevier Science & Technology Books.
- Shoemaker, S. (1970) Persons and their pasts. *American Philosophical Quarterly* (7):269-285.
- Shapiro, T. (2006) Kantian rigorism and mitigating circumstances. *Ethics* 117 (October):32-57.
- Shrader-Frechette, K. (1991a) Reductionist approaches to risk. In *Acceptable evidence*, edited by Mayo, D.G. & Hollander, R.D Oxford: Oxford university press.
- (1991b) *Risk and Rationality: the philosophical foundations for populist reforms*. Berkeley: University of California Press.
- (2002) *Environmental justice. Creating equality, Reclaiming democracy*. Edited by K. Shrader-Frechette, *Environmental Ethics and science policy series*. Oxford: Oxford University Press.
- Silbergeld, E.K. (1991) Risk assessment and risk management: an uneasy divorce. In *Acceptable evidence*, edited by Mayo, D.G. & Hollander, R.D Oxford: Oxford University Press.
- Slovic. (1987) Perception of risk. *Science* 236:280-285.

## Respect for Autonomy and Technological Risks

- (1999) Trust, emotion, sex, politics and science: surveying the risk assessment battlefield. *Risk analysis* 19 (4):689-701.
- (2003) Going beyond the red book: sociopolitics of risk. *Human and ecological risk assessment* 9 (5):1-10.
- Sommerville, M A. (2005) *Therapeutic and non-therapeutic medical procedures-- what are the distinctions?* 1981 [cited 11-02 2005].
- Sunstein, C. (2005) Cost-benefit analysis and the environment. *Ethics* 115:335-385.
- Taylor, C. (1989) *Sources of the self: the making of modern identity*. Cambridge: Harvard University Press.
- (1994) The politics of recognition. In *Multiculturalism*, edited by A. Gutman. Princeton: Princeton University Press.
- Teule, G. (2003) *GSM, straling en de grondwettelijke onaantastbaarheid van ons lichaam*. Tilburg: Sigma/De Ster.
- Thomas, J.A. & Walton, D. (2007) Measuring perceived risk: Self-reported and actual hand positions of SUV and car drivers. *Transportation research F* DOI: 10.1016/j.trf.2006.10.001.
- Tomlinson, N. (2000) Topic 1: the concept of substantial equivalence, its historical development and current use. In *Joint FAO/WHO expert consultation on Foods derived from biotechnology*: FAO/WHO.
- Tonak, A. (2004) *Contamination at Berkeley: the profit motive, academic freedom and the case of Ignacio Chapela* Available from [http://www.counterpunch.org/tonako626\(2004\)html](http://www.counterpunch.org/tonako626(2004)html). [Accessed 15 November 2007]
- Tonne, R. (1985) Measles virus infections without rash in childhood is related to disease in adult life. *The Lancet* 325 (8419):1-5.

- Turnhout, E & Leroy, P. (2004) *Participeren in onzekerheid*. Bilthoven: RIVM.
- Verweij, MF. (2000) Ethische uitgangspunten voor het collectieve vaccinatieprogramma. *Infectieziekten bulletin*, 258-261.
- Wandall, B. (2004) Values in science and risk assessment. *Toxicology letters* 152:265-272.
- Wartenberg, T.E. (1992) Reason and the practice of science. In *The Cambridge Companion to Kant*, edited by P. Guyer. Cambridge: Cambridge University Press.
- Weijer, C & Miller, PB. (2004) Protecting communities in pharmacogenetic and pharmacogenomic research. *The pharmacogenomics journal* (4):9-16.
- Wendt, A. (2004) The state as person in international theory. *Review of International Studies* (30):289-316.
- Wiedemann, P.M. & Schutz, H. (2005) The precautionary principle and risk perception: experimental studies in the EMF area. *Environmental Health Perspectives* 113 (4):402-405.
- Williams, B. (1981) *Moral Luck*. Cambridge: Cambridge University Press.
- Williams, S H. (2004) *Truth, autonomy and speech*. Edited by R. Delgado, & Stefancic, J., *Critical America*. New York: New York University Press.
- Wolfe, R.M, & Sharp, L.K. (2002) Anti-vaccinationists, past and present. *British Medical Journal* 325 (aug 24):430-432.
- Wolfe, R.M, Sharp, L.K. & Lipsky, M.S. (2002) Content and Design Attributes of Anti-vaccination Web Sites. *Journal of the American Medical Association* 287 (24):3245-3248.
- Wong, J. (2003) *Are biotech crops and conventional crops like products? an analysis under GATT*. Duke University School of law Available from

## Respect for Autonomy and Technological Risks

<http://www.law.duke.edu/journals/dltr/articles/2003dltr0027.html>.  
[Accessed 27 January 2006]

Wynne, B. (1980) Technology, risk and participation: on the social treatment of uncertainty. In *Society, technology and risk assessment*, edited by J. Conrad. London: Academic Press.

---- (1996a) May the sheep graze safely: a reflexive view on the expert-lay knowledge divide. In *Risk, Environment and Modernity*, edited by S. Lash, Szerszynski, B. & Wynne, B, London: Sage

---- (1996b) Misunderstanding misunderstandings: social identities and public uptake of science. In *Misunderstanding science? The public reconstruction of science and technology*, edited by A. W. Irwin, B. Cambridge: Cambridge university press.

---- (2002) Risk and environmental issues as STS Themes: reflexivity on the rocks? *Current sociology* 50: 459-477

Zampetti, B. (2003) Democratic legitimacy in the World Trade Organization: The justice dimension. *Journal of World Trade* 37 (1):105-126.

Zwamborn, APM *et al.* (2003) Effects of global communication system radio-frequency fields on well being and cognitive functions of human subjects with and without subjective complaints. The Hague: Netherlands Organisation for Scientific Research.

# Summary

## Respect for autonomy and technological risks

Although technological developments can be seen in many ways as enhancing the autonomy of human beings, through for instance increased mobility, communicative opportunities and enhanced health practices, they have also been identified as possibly undermining the autonomy of the individual. Autonomy is one's ability to make and act upon decisions according to one's own moral framework. Respect for autonomy dictates that risks should not be imposed on the individual without her consent.

Technological developments can bring about risks, which often confront the individual in ways beyond individual control. Democratic institutions and market mechanism fail to offer sufficient means to influence technological risks by laypeople (see Sclove: 1995; Shrader-Frechette: 2002; Feenberg: 1995). This research deals with the question: How should autonomy be respected in the context of technological risks?

It is argued in this thesis that respect for autonomy requires amending current decision procedures on the acceptability of risks. These amendments should be based on a specific, original concept of autonomy; narrative autonomy. Narrative self-understanding forms the core of this concept of autonomy. Traditional concepts of autonomy offer valuable starting points for considering respect for autonomy in the context of technological risks, but they also create problems which can be remedied using the concept of narrative autonomy. Recommendations for decision procedures can be derived from this concept to respect individual autonomy adequately in relation to technological risks.

### *Existing decision procedures*

Two main existing efforts can be identified which aim to improve respect for autonomy in relation to decision procedures on technological risk. Firstly, some authors (see Martin & Schinzinger: 1983) have suggested that the procedure of Informed Consent (IC) might be applied in technological practice. This procedure is widespread in medical practice, where treatments and research also produce risks. Individual patients can consent or dissent to a particular



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treatment or research, after they have been informed by their physician about the associated risks.

The second effort to improve the inclusion of laypeople in decision procedures on technological developments is an array of comparable procedures known as Participatory Technology Assessment (PTA). These procedures include consensus conferences, citizen panels and public debates.

Both of the two efforts described above is worthwhile, but they are lacking in two important respects. One, IC and PTA do not suffice to accommodate individual autonomy because all three stages of risk assessment should be open to input from laypeople to accommodate autonomy and to ensure epistemic quality (see Wynne: 2002; Shrader-Frechette: 1991b, 2005; Kleinmann: 2000). This is currently not the case in IC and only in a limited form in PTA.

Two, the arguments presented in decision procedures on the acceptability of risks should be assessed on quality, something that is currently not done, or at least not explicitly. Such an assessment is required because individual decisions in this context might have consequences for other individuals. I will discuss these reasons in turn.

With regard to one: decisions on the acceptability of risk are mostly achieved through the procedure of risk assessment. Risk assessment usually consists of three stages: identification, estimation and evaluation of risk (see Shrader-Frechette: 1991a). In this research the first two stages are categorized as the *representation* of risk because they determine how a risk is defined. The last stage concerns the moral question on the acceptability of a risk. The way a risk is represented will strongly influence the perception of its acceptability.

Risks attached to a specific technological development can be represented in various ways, many of which may be viable. Knowledge of risk necessarily relies on assumptions about, for instance, expected human behavior, causal chain of events, lag period between cause and effect and models capturing complex interaction relations. These assumptions are a necessary element of risk assessment; they do not undermine the validity of risk assessment. Which assumptions underlie the representation of risk depends on the worldview of the assessor.

In order to respect autonomy it is necessary to acknowledge these different perspectives when scientifically investigating technological risks. In this way the possibility would be greatly reduced that some judgments on the acceptability of risk are marginalized. If those who wield the resources to investigate risks are

the only ones who define the representation of risks, the opportunity for others to influence the decision on the acceptability of risks is severely limited, thereby undermining individual autonomy.

Such an approach will also benefit the epistemic quality of risk assessment. As many authors have argued (e.g. Wynne: 1996b; Shrader-Frechette: 2002; Kleinmann: 2000), laypeople can very often offer useful additions to scientifically produced representations of risk. Moreover, laypeople often invoke relevant moral considerations that are not always incorporated in conventional risk-evaluations.

The procedure of IC in medical practice is supposed to concern only the last stage of risk assessment: the evaluation of risk. In PTA, which consists of efforts to involve laypeople in the evaluation of technological developments, all three stages of risk assessment are open to evaluation by laypeople. In PTA usually several experts inform laypeople about the technology and the associated risk and benefits. This ensures that different perspectives that exist with respect to a technology are all brought forward. In this way, the first two stages of risk assessment are also opened for the input by laypeople since they can decide for themselves which representation they deem most applicable. Whereas in IC the individual patient is presented with one perspective on a risk, in PTA the individual is presented with several perspectives on a risk.

However, PTA-participants only get to choose between the different perspectives presented to them. They are not invited to present their own, original perspectives on the risks associated with the technological development (Kleinmann: 2000). The presentation of risk is confined to scientifically trained individuals: this is insufficient to ensure respect for autonomy for all participants.

The second deficit of existing decision procedures such as IC and PTA is that the judgments of the involved individuals are usually not assessed on quality. IC stars only one person: the individual patient. The decisions made mostly affect an individual's own body and therefore they alone should be the one making those decisions. In technological practice, most decisions by the individual will have direct consequences for other individuals. If I deem a certain technology unacceptable because of associated risks, while you deem that technology desirable in spite of the associated risks, we have a conflict. The assessment of risks tends to be more complicated in technological practice than in medical practice.

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In the kind of decision procedures related to technological risks where the judgment of one individual has consequences for other individuals, it is desirable to subject these judgments to critical appraisal. Claims about the acceptability of risk will have to be recognized as autonomous judgments for them to carry a moral weight for other people, since the value of respect for autonomy is considered to form the moral basis for public decision procedures on technological risks.

### *The need for a new concept of autonomy*

To respect autonomy in the context of technological risks requires a concept of autonomy that offers a basis to formulate constraints on judgments so that non-autonomous judgments can be distinguished from autonomous judgments. At the same time, such a concept should accommodate diversity, to respect the diversity in perspectives on risk and hence the autonomy of the divergent actors.

Although existing concepts of autonomy such as those formulated by Mill, Kant and feminist authors offer valuable starting points for such a concept, some important drawbacks remain. In this research another concept of autonomy is proposed which combines the desired qualities of the above mentioned concepts. It incorporates the strengths of the existing concepts, while offering a framework to improve on the drawbacks of the existing concepts. This new concept of autonomy is named narrative autonomy, as it puts identity and the construction of identity through narratives at the heart of individual autonomy.

Three existing accounts of autonomy offer valuable starting points for a useful concept of autonomy in the context of technological risks. Mill's conception of autonomy is very much an effort to accommodate diversity. Kant's concept of autonomy is basically a constraint on autonomously made arguments. These two concepts are powerful and resilient, but they have also been criticized as presupposing a rather isolated individual. Originating in this criticism, feminist authors have introduced concepts of autonomy that incorporates social relations. In the context of technological risk, where each decision of an individual affects other individuals, the incorporation of social relations appears valuable. Although these qualities of these existing concepts are useful, some drawbacks remain. I will discuss the three concepts in turn.

Mill is an ardent defender of respect for diversity: individuals should not be oppressed by a conception of the good life that is not theirs. Mill sought to protect the freedom of the individual through the demand that any interference,

whether by the state or by other individuals, with autonomy has to be justified, either through consent of the individual or with reference to the harm principle. This latter principle states that interference is justified when applied to avoid harm to third parties.

Basically Mill argued that any reason for interference needs to be conclusively justified (Gaus: 1996), implying that all the relevant actors can reasonably consent to that reason, considering their own particular moral framework. The concept of harm may provide a reason to which everybody can consent. However, the concept of harm itself can also be contested and questioned considering various perceptions on the good life. What I deem harmful may not appear harmful to you.

As feminist authors have argued (Williams: 2004) the problem with this approach is that it turns a blind eye to social inequalities. Firstly, to change social inequalities requires interference with existing situations, which actors who benefit from that situation will refuse. Hence it will be difficult to achieve conclusive justification. Secondly, not all parties will be equally able to argue convincingly for their case. To this I want to add that this is especially the case in the context of technological risks.

Mill argued that the burden of proof is on those seeking to interfere with others through legislation. However, some parties have better access to the means to support their arguments with the necessary support. In modern societies this would be scientific research to sustain the case for the existence of a possible harm. The Millian concept of autonomy fails to take into account the internal aspect of autonomy, i.e. the capacities and resources an individual needs in order to lead an autonomous life, by focusing on the protection of external autonomy, i.e. the freedom from impositions.

Feminist authors have criticized Millian autonomy on aspects such as mentioned above for being overly individualistic and for taking an idealized, advantaged, isolated individual as starting point. They propose instead to consider autonomy a relational concept. An individual is autonomous because of and through the relationships she maintains. Relationships give meaning and guidance to an individual's life.

I agree with the feminist that relationships are an important element of autonomy, however, this approach creates other problems. Conceiving of autonomy as the product of contingent circumstantial influences makes autonomy an empty concept, which leaves little room to distinguish between

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autonomous and non-autonomous judgments and actions. Relationships are flexible and mutable and come in all kinds: they can be treacherous and debilitating for individual autonomy. Relationships do not necessarily give guidance on how to act on them, they may be interpreted differently by different actors. For instance, most feminists reject any relationships that involve submission to male partners. However, some women are brought up in social environments which propagate inequality between men and women. Submission might very well be an act of autonomy, if autonomy is caused and shaped by the relationships the individual maintains. The relational concept of autonomy lacks a ground to dismiss some actions and judgments as non-autonomous.

In contrast, Kant's concept of autonomy mainly consists of constraints to distinguish autonomously made claims from non-autonomously made claims. He states that only those judgments whose worth is not contingent upon a particular situation or the identity of the individual are truly autonomous judgments. These judgments are autonomous because they are valuable independently of external influences.

Truly autonomous judgments meet requirements of the categorical imperative. The relevant formulation of the categorical imperative in this context, the first formulation or the formula of autonomy, is: "Act only according to that maxim whereby you can at the same time will that it should become a universal law".

The problem with Kant's categorical imperative is that it does not take into account that social context provides moral meaningfulness. The categorical imperative allows for a wide range of judgments, but for people to be able to arrive at a judgment at all, they need the moral categories and narratives that are handed to them by their environment. In forming judgments, people are guided by their personal identity, which is shaped by their social background. External influences are not an obstacle to autonomous judgments, they are a prerequisite. Morality itself is shaped by social structures and personal identity.

Therefore, social context and identity should be taken into account when assessing the autonomy of judgment. Constraints based on the concept of identity are more true to actual moral decision making. As such they offer more resources to structure decision procedures on the evaluation of risk: they provide more specific guidance to assess the moral judgments. This guidance is related to the social context within which the decision procedure is situated. This point

is illustrated in the case-study on vaccination and the case-study on mobile phone technology.

### *Narrative autonomy*

The concept of narrative autonomy incorporates Millian respect for diversity, feminist recognition of the social embeddedness of individuals and Kant's demand for constraints on autonomous judgments, while overcoming the drawbacks of these accounts. In the concept of narrative autonomy respect for diversity is embodied in the recognition of the existence of a diversity of individual perspectives, each person has her own narrative identity. This identity forms the basis of autonomy and should be respected. This implies that divergence in capacities have to be respected. Social embeddedness is captured by the relation between personal narratives and social-cultural narratives. Lastly, the concept of narrative identity also allows to put constraints on narratives.

Identity is the way a person conceives of herself. Identity guides individuals in making decisions and evaluating situations: individuals will make those decisions that reaffirm the way they understand themselves (cf. Korsgaard: 1992). Identity consists of narratives: storylines that connect seemingly unrelated events into a coherent meaningful whole (see Schechtman: 1996). Individual narratives are constructed from social and cultural narratives, which structure entire societies. Individual narratives can deviate from such social narratives, but they will always derive their meaning from social narratives. As such, the ability to make and enact decisions according to the individual's own personal framework results from the social embeddedness of the individual.

Following Marya Schechtman (1996), a narrative is considered to be identity constituting only when the underlying narrative lives up to two constraints: the reality constraint and the articulation constraint. The reality constraint basically implies that narratives should cohere with fundamental aspects of reality. The articulation constraint basically implies that narratives should be coherent and intelligible to others.

I explicate these two constraints further with reference to Anthony Laden's form and content features of identity (see Laden: 2001). Form features are those aspects of identity that are externally dictated: they are inalienable elements of a stable society and they are usually theoretically underpinned, for instance the legal obligations between married persons. There is little room for the individual to alter these aspects of identity, although if it should be necessary, such changes

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are possible. Content features of identity refer to those aspects of identity that are open to individual interpretation; such as the actual interaction between married persons.

Individual narratives have to respect the form features of relevant identities and identity supporting social-cultural narratives in order to constitute a meaningful social identity. Only then can the individual be understood as an autonomous individual in charge of her own life. As such, narrative autonomy offers a basis to formulate constraints on the arguments and claims of individuals. Specific recommendations with regard to decision procedures on the acceptability of risk can be derived from the concept of narrative autonomy, which are intended to increase respect for autonomy. How the form and content features map onto the Constraints exactly will be described in the next section.

### *Decision procedures on the acceptability of risk*

Decisions on the acceptability of risks that are in line with respect for autonomy consist of public and political debates. These debates have to be structured according to three main recommendations. One, only arguments that meet the constraints based on narrative identity should be respected as autonomous judgments. Two, criteria for the representation of risk need to be flexible and open to debate. Three, the burden of proof needs to be appointed according to capacity.

In public debates, individuals can share arguments and exchange claims about risks. They can present their own perspective on a particular risk. The actual decisions regarding the acceptability of risks are made during the political debate. Public debates can be said to coincide with the first two stages of risk assessment, i.e. representation of risk, political debates can be said to coincide with the third stage of risk assessment; the evaluation of risk. Public debates precede the political debate, only those arguments that can be recognized as autonomously made arguments are imported into the political debate.

Autonomously made arguments and claims in the public debate are those arguments that live up to the reality and the articulation constraints. The reality constraint consists of the epistemic values of scientific practice. Science is a knowledge producing practice of modern societies. This is not to say that science always produces truth or that science alone can produce truth, but in our society it has become the means by which to produce knowledge in a systematic way, building on expertise from various actors, especially when it comes to

technological risks. The form features of scientific practice are the epistemic values that underlie all scientifically produced knowledge. Claims made about the existence of a specific risk should be compatible with the form features of science.

The reality constraint allows for a range of perspectives on the risks associated with a similar technological developments. Accepting variety in the representation of risk as informative for the political debate allows more room for diversity than accepting only supposedly neutral representations which should elicit widespread consent. This point is illustrated in the case-study on genetically modified organisms.

The articulation constraint works out differently in the two kinds of debates. In the public debate, the articulation constraint demands coherence and intelligibility of the different arguments and the way they relate to relevant identities. Form features of relevant public identities need to be respected. However, in the public debate, people act mostly out of their particular (private) identities. Although particular identities may also be constrained by form features, these are usually normatively less authoritative than the form features associated with identities that are entirely public in character.

In the political debate, such entirely public identities are of paramount importance, for this debate the form features of citizenship should be respected as individuals participate in this debate out of their identity as citizen. These form features consist of the fundamental political values within a society. These values enable citizens to reciprocally make claims and construct a viable society together and hence their endorsement by everyone is indispensable for the functioning of that political community. In the case of western, modern societies the fundamental political values amount to: respect for autonomy, equality, justice and non-malificence. These values furthermore have the quality of overridingness: they override any other values they might come into conflict with.

Through reference to these shared social values the notion of identity offers a basis to justify interferences without necessarily requiring conclusive justification. Anybody entering the political debate should respect these form features of political identity. Such shared social values can also be said to be based on conclusive justification, but in a way that is more solid than individual consent. The basis on which a society rests is articulated and all members are assumed to subscribe to that basis or offer strong reasons to alter the basis. In



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case of conflicts, it should be clear that the four basic values take precedence over any other values. They need not be argued for each and every time, and if they are contested, it is clear where the burden of proof lies. As such, shared political values embody a perspective of the good life, but one that can be expected to elicit consent from all members within a society. The value of this approach is illustrated in the case on mobile phone technology and in the vaccination case. The procedure of conclusive justification will lead to undesirable outcomes by making it impossible to demand that individuals take the perspective of others into account.

Introducing the notion of identity has another beneficial effect with regard to decision procedures on technological risks: by considering the capacities of divergent actors, which derive from their identities, the burden of proof can be appointed in a way that respects autonomy better. Put differently: the burden of proof should be placed on those actors most capable to produce particular pieces of evidence as required in debates on the acceptability of technological risks. Parties with fewer resources to invest in scientific research, such as laypeople, should not be the ones who have to organize and pay for scientific research, and they should be allowed to influence the set-up of such research as long as their input respects the relevant constraints. This point is illustrated in the case studies on GMOs and mobile phone technology.

How this concept of narrative autonomy works out in practice is explicated in the case studies. The first case study, on the trade-conflict between the United States of America and Europe on the import of GMOs, shows that it is important to respect diversity in perspectives on risk. The second case study, on the debate of vaccination of children, illustrates the use of constraints in a context where individual decisions have consequences for a larger group of people. The analysis of the last case-study concerning the debate on risks associated with mobile phone technology integrates all elements of narrative autonomy. It shows how important the issue of identity is for understanding and evaluating debates on the acceptability of technological risks.

# Samenvatting

Alhoewel technologische ontwikkelingen beschouwd kunnen worden als versterkingen van de autonomie van mensen, bijvoorbeeld door toenemende mobiliteit en mogelijkheden voor communicatie en verbeterde gezondheidszorg, zijn ze ook aangeduid als een bedreiging voor individuele autonomie. Autonomie is de vaardigheid om beslissingen te nemen en daarnaar te handelen volgens het eigen morele raamwerk. Respect voor autonomie dicteert dat risico's niet aan het individu opgelegd mogen worden zonder haar toestemming.

Technologische ontwikkelingen kunnen risico's met zich meebrengen, waarmee het individu zich vaak buiten haar eigen controle om, mee geconfronteerd ziet. Democratische instituties en marktmechanismen bieden onvoldoende mogelijkheden aan leken om technologische ontwikkelingen te beïnvloeden (zie Sclove: 1995; Shrader-Frechette: 2002; Feenberg: 1995). Dit onderzoek handelt over de vraag: Hoe moet autonomie worden gerespecteerd in the context van technologische risico's?

In dit proefschrift wordt betoogd dat respect voor autonomie veranderingen vereist van bestaande besluitvormingsprocedures over de aanvaardbaarheid van technologische risico's. Deze veranderingen moeten worden afgeleid van een specifiek, origineel concept van autonomie: narratieve autonomie. Narratief zelfbegrip vormt de kern van dit concept van autonomie. Traditionele concepten van autonomie vormen waardevolle aanknopingspunten om respect voor autonomie in de context van technologische risico's te overdenken, maar zij leveren ook problemen op die verholpen kunnen worden door het concept van narratieve autonomie te gebruiken. Narratieve autonomie vormt een basis voor aanbevelingen voor besluitvormingsprocedures om autonomie adequaat te respecteren in relatie tot technologische risico's.

## *Bestaande besluitvormingsprocedures*

Er bestaan twee belangrijke pogingen om respect voor autonomie te verbeteren in relatie tot besluitvormingsprocedures over technologische risico's. Ten eerste stellen sommige auteurs (zie Martin & Schinzinger: 1983) voor om de procedure van Informed Consent (IC) in te voeren in de technologische praktijk. Deze procedure is wijdverbreid in de medische praktijk, waar behandeling en

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onderzoek ook risico's met zich meebrengen. Individuele patiënten kunnen instemmen, of niet, met een bepaalde behandeling of onderzoek, nadat ze zijn geïnformeerd door hun dokter over de bijbehorende risico's.

The tweede poging om de invloed van leken op besluiten over de aanvaardbaarheid van technologische risico's te verbeteren is een verzameling van vergelijkbare procedures die bekend staan als Participatory Technology Assessment (PTA). Deze procedures bevatten consensus conferenties, burgerpanels en publieke debatten.

Beide pogingen die hierboven beschreven zijn, zijn waardevol, maar schieten tekort op twee belangrijke aspecten. Ten eerste zouden alle drie de fasen van risk assessment open moeten staan voor de inbreng van leken om autonomie te respecteren en om epistemische kwaliteit te garanderen (zie Wynne: 2002; Shrader-Frechette: 1991b, 2005; Kleinmann 2000). Dit is momenteel bij IC helemaal niet aan de orden en bij PTA slechts in beperkte mate.

Ten tweede moeten de argumenten die in besluitvormingsprocedures over de aanvaardbaarheid van technologische risico's gepresenteerd worden, getoetst worden op kwaliteit. Dit gebeurt momenteel niet, of in ieder geval niet expliciet. Een dergelijke toetsing is vereist omdat individuele oordelen in deze context gevolgen kunnen hebben voor andere individuen. Ik zal beide redenen nu verder toelichten.

Met betrekking tot de eerste reden: besluiten over de aanvaardbaarheid van technologische risico's worden meestal gemaakt door middel van de procedure van risk assessment. Risk assessment bestaat doorgaans uit drie fasen: identificatie, schatting en evaluatie van een risico (zie Shrader-Frechette: 1991a). In dit onderzoek worden de eerste twee fasen gecategoriseerd als de representatie van risico omdat deze fasen bepalen hoe een risico wordt gedefinieerd. De derde fase gaat over de morele vraag aangaande de aanvaardbaarheid van een risico. De manier waarop een risico is gedefinieerd bepaalt in sterke mate de perceptie van zijn aanvaardbaarheid.

Risico's die met een technologische ontwikkeling geassocieerd worden, kunnen op verschillende manieren gepresenteerd worden, waarvan vele houdbaar kunnen zijn. Kennis over technologische risico's stoelt noodzakelijkerwijs op aannames over, bijvoorbeeld, verwacht menselijk gedrag, oorzakelijk keten van gebeurtenissen, de vertragende periode tussen oorzaak en gevolg en modellen die complexe interactie relaties beschrijven. Deze aannames zijn een noodzakelijk element van risk assessments: ze ondermijnen niet de

houdbaarheid van risk assessments. Welke aannames de representatie van een risico bepalen, hangt af van wereldbeschouwing van de onderzoeker of beoordelaar.

Om autonomie te respecteren is het nodig dat bij wetenschappelijk onderzoek naar risico's de verschillende perspectieven op risico's erkend worden. Dit om te vermijden dat sommige perspectieven op de aanvaardbaarheid van een risico gemarginaliseerd worden. Als degenen die over de middelen beschikken om risico's wetenschappelijk te onderzoeken de enigen zijn die de representatie van risico's definiëren, dan zijn anderen behoorlijk beperkt in hun mogelijkheden om de beslissing over de aanvaardbaarheid van de risico te beïnvloeden.

Een dergelijke aanpak zal ook ten goede komen aan de epistemische kwaliteit van risk assessment. Zoals veel auteurs al beargumenteerd hebben (b.v. Wynne: 1996b; Shrader-Frechette: 2002; Kleinmann: 2000), kunnen leken vaak waardevolle bijdragen leveren aan wetenschappelijk geproduceerde representaties van risico's. Daarbij benoemen leken vaak morele overwegingen die niet altijd meegenomen worden in conventionele evaluaties van risico's.

De procedure van IC wordt geacht enkel de laatste fase van risk assessment te beslaan, namelijk de evaluatie van een risico. Bij PTA, dat bestaat uit pogingen om leken te betrekken bij de evaluatie van technologische ontwikkelingen, zijn alle drie de fasen van risk-assessment in principe open voor evaluatie door leken. In PTA informeren doorgaans verschillende experts leken over een technologische ontwikkelingen en de bijbehorende voordelen en risico's. Deze aanpak garandeert dat verschillende perspectieven ten aanzien van een technologie naar voren gebracht worden. Op deze manier staan ook de eerste twee fasen van risk assessment open voor input van leken omdat ze zelf kunnen besluiten welke representatie ze het meeste aanspreekt. Terwijl de individuele patiënt in IC in principe één perspectief gepresenteerd krijgt, krijgt het individu bij PTA verschillende perspectieven voorgeschoteld. Echter, deelnemers aan PTA kunnen alleen kiezen tussen die verschillende perspectieven. Ze worden niet uitgenodigd om hun eigen, originele perspectief op technologische risico's te presenteren (zie Kleinmann: 2000). De presentatie van risico is voorbehouden aan wetenschappelijk opgeleide individuen: dit is niet voldoende om respect voor de autonomie van alle deelnemers te garanderen.

Het tweede tekort van bestaande besluitvormingsprocedures zoals IC en PTA is dat de oordelen van betrokken individuen doorgaans niet (expliciet)

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beoordeeld worden op kwaliteit. IC betreft slechts één persoon: de individuele patiënt. De genomen besluiten betreffen voornamelijk het lichaam van dat individu en daarom zou dat individu alleen de besluiten moeten nemen. In de technologische praktijk hebben de meeste besluiten van individuen directe consequenties voor anderen. Als ik een bepaalde technologie onacceptabel vind vanwege de risico's, terwijl jij die technologie verwelkomt vanwege de voordelen, dan hebben we een conflict. De beoordelingen van risico's is doorgaans gecompliceerder in de technologische dan in de medische praktijk.

In het soort besluitvormingsprocedures rondom technologische risico's, waar het oordeel van een individu consequenties heeft voor andere individuen, is het wenselijk om die oordelen te onderwerpen aan een kritische toetsing. Beweringen over de aanvaardbaarheid van technologische risico's moeten erkend worden als autonome beweringen voordat ze geacht kunnen worden moreel gewicht te hebben voor andere mensen, omdat autonomie geldt als de morele basis publieke besluitvormingsprocedures over technologische risico's.

### *De noodzaak voor een nieuw concept van autonomie*

Respect voor autonomie in de context van technologische risico's vereist een concept van autonomie dat een basis biedt om beperkingen op oordelen te formuleren zodat een onderscheid gemaakt kan worden tussen autonome en niet-autonome oordelen. Tegelijkertijd moet een dergelijk concept ruimte bieden voor diversiteit, zodat de diversiteit in perspectieven op risico's en daarmee de autonomie van de verschillende actoren gerespecteerd kan worden.

Alhoewel bestaande concepten zoals geformuleerd door Mill, Kant en feministische auteurs waardevolle aanknopingspunten bieden voor een dergelijk concept, blijven enkele belangrijke knelpunten over. In dit proefschrift wordt een ander concept van autonomie ontwikkeld, dat de wenselijke eigenschappen van de andere concepten combineert, terwijl het een raamwerk biedt om de knelpunten te verbeteren. Dit nieuwe concept van autonomie heet narratieve autonomie, omdat het identiteit en de vorming van identiteit door narratieven in het hart van individuele autonomie plaatst.

Drie bestaande concepten bieden waardevolle aanknopingspunten voor een bruikbaar concept van autonomie in de context van technologische risico's. Mill's concept van autonomie is een sterke poging om diversiteit te accommoderen. Kant's concept van autonomie is basaal gezien een beperking op autonoom gemaakte oordelen. Deze twee concepten zijn krachtig en duurzaam

gebleken, maar ze zijn ook bekritiseerd omdat ze een tamelijk geïsoleerd individu veronderstellen. Vanuit deze kritiek hebben feministische auteurs concepten van autonomie geïntroduceerd die sociale relaties insluiten. In de context van technologische risico's, waar elke individuele beslissingen andere individuen beïnvloedt, lijkt een focus op sociale relaties waardevol. Alhoewel de bovengenoemde eigenschappen van de bestaande concepten bruikbaar zijn, blijven enkele knelpunten over. Ik zal de drie concepten om beurten bespreken.

Mill is een verwoed voorvechter van respect voor diversiteit: individuen zouden niet onderdrukt moeten worden door een idee van het goede leven dat niet van hen is. Mill probeerde de vrijheid van individuen te beschermen door de eis dat enige inmenging met autonomie, zij het door de staat of door andere individuen, geëgitimeerd moet worden, hetzij door toestemming van het individu of door een verwijzing naar het schadeprincipe. Dit laatste principe zegt dat inmenging geëgitimeerd is wanneer het wordt toegepast om schade aan derden te voorkomen.

Basaal gezegd betoogde Mill dat iedere reden voor inmenging overtuigend onderbouwd moest worden (zie Gaus: 1996). Dit houdt in dat alle relevante actoren redelijkerwijs in kunnen stemmen met de betreffende reden, uitgaande van hun eigen, particuliere morele raamwerken. Schade zou een grond voor dergelijke instemming kunnen zijn. Echter, het concept schade kan zelf ook betwist en bevreemdend worden, gezien de verschillende perspectieven op het goede leven. Wat ik als schadelijk beschouw, hoeft dat voor jou niet te zijn.

Zoals feministische auteurs hebben betoogd (zie Williams: 2004) ligt het probleem met deze benadering erin dat het een blinde vlek heeft voor bestaande sociale ongelijkheden. Ten eerste vereist het veranderen van bestaande sociale ongelijkheden inmenging met een bestaande situatie, iets waar de actoren die van die situatie profiteren zich tegen zullen verzetten. Het zal moeilijk zijn om hun instemming met een dergelijke verandering te krijgen. Ten tweede zijn niet alle partijen gelijkelijk in staat om overtuigend voor hun belang te betogen. Ik wil hieraan toevoegen dat dit met name het geval is in de context van technologische risico's.

Mill betoogde dat de bewijslast ligt bij degenen die inmenging met de autonomie van anderen voorstellen. Echter, sommige partijen hebben betere toegang tot de middelen om hun argumenten kracht bij te zetten dan anderen. In moderne samenlevingen bestaan dergelijke middelen uit wetenschappelijk onderzoek om het bestaan van een veronderstelde schade te ondersteunen. Het

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Milliaanse begrip van autonomie veronachtzaamd het interne aspect van autonomie, namelijk de vaardigheden en middelen die een individu nodig heeft om een autonoom leven te leiden, door te focussen op het externe aspect van autonomie, namelijk de vrijwaring van inmenging.

Feministische auteurs hebben Mill bekritiseerd op aspecten zoals hierboven genoemd zijn vanwege zijn sterke individualisme en omdat hij een geïdealiseerd, bevoordeeld, geïsoleerd individu als uitgangspunt neemt. De feministische auteurs stellen in plaats daarvan voor om een autonomie als een relationeel concept te begrijpen. Een individu is autonoom vanwege en door de relaties die ze onderhoudt met andere mensen. Menselijke relaties geven betekenis en richting aan het leven van een individu.

Ik ben het met de feministen eens dat relaties een belangrijk onderdeel uitmaken van autonomie, echter, deze benadering leidt tot andere problemen. Als autonomie begrepen wordt als het product van toevallige omgevingsfactoren, verwordt autonomie tot een leeg begrip dat weinig ruimte biedt om onderscheid te maken tussen autonome en niet-autonome oordelen en acties. Relaties zijn flexibel en veranderlijk en ze bestaan in alle soorten en maten: ze kunnen verraderlijk zijn en individuele autonomie ondermijnen. Relaties geven niet noodzakelijk inzicht in hoe we met relaties om moeten gaan, ze kunnen verschillend geïnterpreteerd worden door verschillende mensen. Bijvoorbeeld, de meeste feministen verwerpen een relatie die onderwerping aan een mannelijke partner inhoudt. Echter, sommige vrouwen groeien op in sociale omgevingen waar ongelijkheid tussen man en vrouw gepropageerd wordt. In dat geval kan onderwerping begrepen worden als een autonome keuze, als autonomie inderdaad gevormd en veroorzaakt wordt door de relaties die het individu onderhoudt. In het relationele concept van autonomie ontbreekt een grond om sommige acties als niet-autonoom te verwerpen.

Kant's concept van autonomie daarentegen, bestaat hoofdzakelijk uit beperkingen om autonoom gemaakte oordelen te onderscheiden van niet-autonoom gemaakte oordelen. Hij beweert dat enkel die oordelen wiens waarde niet afhankelijk is van de specifieke situatie of de identiteit van het individu werkelijk autonoom zijn. Dergelijke oordelen zijn autonoom omdat ze waardevol zijn ongeacht externe omgevingsfactoren.

Werkelijk autonome oordelen voldoen aan de categorische imperatief. De relevante formulering van de categorisch imperatief in deze context, de eerste

formulering oftewel de formule van autonomie, luidt: “Handel enkel volgens dat maxim waarvan je kan willen dat het een universele wet is.”

Het probleem met Kant’s categorische imperatief is dat niet in ogenschouw neemt dat de sociale context morele betekenis geeft. Het categorische imperatief biedt ruimte voor een wijde verscheidenheid aan oordelen, maar om in eerste instantie tot een oordeel te kunnen komen, hebben mensen morele categorieën en narratieven nodig die ze door hun omgeving aangereikt krijgen. In het vormen van morele oordelen worden mensen geleid door hun persoonlijke identiteit, die wordt gevormd door hun sociale achtergrond. Moraliteit wordt gevormd door sociale instituten en persoonlijke identiteit. Externe invloeden zijn geen obstakel voor autonome oordelen, ze vormen een voorwaarde. Daarom moeten sociale context en identiteit meegenomen worden bij het toetsen van de autonomie van een oordeel.

Beperkingen die gebaseerd zijn op het concept identiteit doen meer recht aan daadwerkelijke morele besluitvorming. Als zodanig bieden ze meer aangrijpingspunten om besluitvormingsprocedures rondom de evaluatie van risico’s te structureren. Deze aangrijpingspunten zijn gerelateerd aan de sociale context waarin de besluitvormingsprocedure is gesitueerd. Dit punt wordt geïllustreerd in de case studie over vaccinatie en in de case studie over mobiele telefonie.

#### *Narratieve autonomie*

Het concept van narratieve autonomie omvat Milliaans respect voor diversiteit, feministische erkenning van de sociale inbedding van individuen en Kantiaanse beperkingen op autonome oordelen, terwijl het tegelijkertijd een oplossing biedt voor de knelpunten van deze benaderingen. In het concept van narratieve autonomie wordt respect voor autonomie belichaamt door de erkenning dat er een veelheid aan individuele perspectieven bestaat, aangezien ieder persoon zijn eigen narratieve identiteit heeft. Deze identiteit vormt de basis van autonomie en dient gerespecteerd te worden. Dit betekent dat ook de verschillen in vaardigheden gerespecteerd dienen te worden. Sociale inbedding wordt gevat door de relatie tussen persoonlijke narratieven en sociaal-culturele narratieven. Tot slot biedt het concept van narratieve autonomie ook ruimte voor beperkingen op narratieven.

Identiteit is de manier waarop een individu zichzelf begrijpt. Identiteit geeft individuen richting bij het nemen van beslissingen en bij het evalueren van



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situaties: individuen zullen besluiten nemen die de manier waarop zij zichzelf zien bevestigen (cf. Korsgaard: 1992). Identiteit bestaat uit narratieven: verhaallijnen die schijnbaar losstaande gebeurtenissen met elkaar verbinden tot een betekenisvol geheel. Individuele narratieven worden gevormd met verwijzing naar sociale en culturele narratieven, die hele samenlevingen structuren. Individuele narratieven kunnen afwijken van zulke sociale narratieven, maar ze zullen altijd hun betekenis ontlenen aan sociale narratieven. Als zodanig is de vaardigheid om beslissingen te nemen en daarnaar te handelen volgens het eigen morele raamwerk een gevolg van de sociale inbedding van het individu,

In lijn met het werk van Marya Schechtman (1996) wordt een narratief enkel beschouwd als de basis voor identiteit wanneer het voldoet aan twee beperkingen: de realiteitsbeperking en de articulatiebeperking. De realiteitsbeperking vereist dat narratieven moeten overeenstemmen met fundamentele aspecten van de werkelijkheid. De articulatiebeperking vereist dat narratieven coherent en begrijpelijk voor anderen zijn.

Ik expliciteer deze beperkingen verder met verwijzing naar Anthony Laden's vorm en inhoud eigenschappen van identiteit (zie Laden: 2001). Vorm eigenschappen zijn die aspecten van identiteit die extern gedictieerd worden: ze zijn onvervreemdbare elementen van een stabiele samenleving en ze zijn doorgaans theoretisch onderbouwd, bijvoorbeeld de wettelijke plichten tussen getrouwde personen. Inhoud eigenschappen bieden meer ruimte voor individuele interpretatie, bijvoorbeeld de daadwerkelijke interactie tussen huwelijkspartners.

Individuele narratieven moeten de vorm eigenschappen van relevante identiteiten en identiteit ondersteunende sociaal-culturele narratieven respecteren om een betekenisvolle sociale identiteit te kunnen vormen. Alleen in dat geval kan het individu beschouwd worden als een autonoom individu die grip heeft op haar eigen bestaan. Als zodanig biedt narratieve autonomie een basis om beperkingen te formuleren op de argumenten en beweringen van individuen.

Specifieke aanbevelingen met betrekking tot besluitvormingsprocedures over de aanvaardbaarheid van risico's kunnen worden afgeleid van het concept van narratieve autonomie. Deze zijn bedoeld om respect voor autonomie te vergroten. Hoe de vorm en inhoud eigenschappen zich verhouden tot de beperkingen zal hieronder toegelicht worden.

*Besluitvormingsprocedures over de aanvaardbaarheid van risico's*

Besluiten over de aanvaardbaarheid van risico's die verenigbaar zijn met respect voor autonomie bestaan uit publieke en politieke debatten. Deze debatten moeten gestructureerd worden volgens drie centrale aanbevelingen. Ten eerste, enkel de argumenten die voldoen aan de beperkingen mogen erkend worden als autonome argumenten. Ten tweede, criteria die de representatie van een risico bepalen moeten flexibel zijn en mogen altijd ter discussie gesteld worden. Ten derde moet de bewijslast aangewezen op een manier die rekening houdt met het vermogen om bewijs te leveren.

In publieke debatten kunnen individuen argumenten uitwisselen en beweringen ten aanzien van risico's verkondigen. Ze kunnen hun eigen perspectief op een specifiek risico presenteren. De daadwerkelijke beslissing ten aanzien van de aanvaardbaarheid van het risico wordt genomen in het politieke debat. Publieke debatten vallen samen met de eerste twee fasen van risk assessment, namelijk de representatie van een risico. Politieke debatten vallen samen met de laatste fase van risk assessment, namelijk de evaluatie van een risico. Politieke debatten worden voorafgegaan door publieke debatten. Slechts die argumenten die als autonoom aangemerkt kunnen worden, worden toegelaten tot het politieke debat.

Autonoom gemaakte argumenten en beweringen in het publieke debat zijn die argumenten die voldoen aan de realiteitsbeperking en de articulatiebeperking. De realiteitsbeperking bestaat uit wetenschappelijke, epistemische waarden. Wetenschap is een waarheidsproducerende praktijk van moderne samenlevingen. Hiermee wil ik niet zeggen dat wetenschap altijd waarheid oplevert of dat de wetenschap alleen waarheid kan produceren, maar in een samenleving als de onze is het een belangrijke manier om kennis op een systematische manier te produceren, daarbij gebruik makend van de expertise van verschillende actoren, in het bijzonder wanneer het over technologische risico's gaat. De vormeigenschappen van de wetenschappelijke praktijk zijn de epistemische waarden waarop alle wetenschappelijke kennis gebaseerd is. Beweringen over het voorkomen van een specifiek risico moeten in overeenstemming zijn met de vormeigenschappen van wetenschap.

De realiteitsbeperking biedt ruimte aan veel verschillende perspectieven op de risico's die met een specifieke technologie geassocieerd worden. Het omarmen van deze variëteit aan perspectieven als informatief voor het politieke

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debat biedt meer ruimte voor diversiteit dan wanneer enkel zogenaamd neutrale representaties van risico zouden worden toegelaten, die wijdverbreide instemming zouden moeten ontlokken. Dit punt wordt geïllustreerd in de case studie over genetische gemodificeerde organismen.

De articulatiebeperking heeft een verschillende uitwerking in ieder soort van debat. In het publieke debat vereist de articulatiebeperking dat de verschillende argumenten en de manier waarop ze verbonden zijn met relevante identiteiten coherent en begrijpelijk zijn. De vormeigenschappen van relevante publieke identiteiten dienen te worden gerespecteerd, echter, in het publieke debat zijn vooral particuliere identiteiten van belang. Hoewel particuliere identiteiten ook beperkt kunnen worden door vormeigenschappen, wordt aan deze vormeigenschappen over het algemeen minder autoriteit toegekend dan aan de vormeigenschappen van identiteiten die geheel publiek van aard zijn.

In het politieke debat zijn zulke publieke identiteiten van groot belang. In deze debatten moeten de vormeigenschappen van burgerschap gerespecteerd worden omdat individuen aan politieke debatten deelnemen in hun hoedanigheid als burger. De vormeigenschappen van burgerschap bestaan uit de fundamentele waarden binnen een samenleving. Deze waarden maken het mogelijk dat burgers een beroep op elkaar kunnen doen en dat ze samen een leefbare samenleving kunnen opbouwen. Het is voor het functioneren van een politieke gemeenschap van vitaal belang dat iedereen deze waarden erkent. In het geval van Westerse, moderne samenlevingen deze waarden bestaan uit: respect voor autonomie, gelijkheid, rechtvaardigheid en niet schaden. Deze vier waarden hebben bovendien de eigenschap van doorslaggevendheid: ze geven altijd de doorslag boven andere waarden waarmee ze eventueel in conflict komen.

Door de verwijzing naar deze gedeelde sociale waarden biedt de notie van identiteit een basis om inmenging te legitimeren, zonder noodzakelijkerwijs overtuigende onderbouwing te eisen. Iedereen die deelneemt aan politieke debatten zou de vormeigenschappen van politieke identiteit moeten respecteren. Dergelijke gedeelde waarden zijn uiteindelijke ook op overtuigende onderbouwing gebaseerd, maar op een manier die meer solide is dan steeds hernieuwde individuele instemming. De morele basis waarop een samenleving rust is expliciet gemaakt en alle leden van die samenleving worden verwacht om die morele basis te onderschrijven of om goede redenen te bieden waarom deze basis anders zou moeten zijn. In het geval van een conflict, geven deze vier

waarden de doorslag boven andere waarden. Ze hoeven niet iedere keer opnieuw onderbouwd te worden en als ze ter discussie gesteld worden, is het duidelijk waar de bewijslast ligt. Als zodanig belichamen de vier waarden een perspectief op het goede leven, maar een waarbij instemming van alle leden van een samenleving verwacht kan worden. De waarde van deze benadering wordt geïllustreerd in de case studie over mobiele telefonie en de vaccinatie case studie. De procedure van overtuigende onderbouwing zou tot onwelkome uitkomsten leiden omdat het moeilijk wordt van individuen te verlangen dat ze het perspectief van anderen in ogenschouw nemen, aangezien niet duidelijk is welke morele basis gedeeld wordt.

De introductie van de notie van identiteit heeft nog een voordeel op besluitvormingsprocedures over technologische risico's: door de capaciteiten van uiteenlopende actoren in ogenschouw te nemen, die voortvloeien uit hun identiteit, kan de bewijslast toegewezen worden op een manier die autonomie beter respecteert. Anders gezegd: de bewijslast zou moeten liggen bij die actoren die het beste in staat zijn om een bepaald bewijs te produceren dat gewenst is in een debat over de aanvaardbaarheid van technologische risico's. Partijen die minder middelen hebben om in wetenschappelijk onderzoek te investeren, zoals leken, zouden niet degenen moeten zijn die wetenschappelijk onderzoek moeten organiseren en betalen. Ze moeten echter wel de mogelijkheid hebben om de opzet van zulk onderzoek te beïnvloeden, mits hun voorstellen voldoen aan de relevante beperkingen. Dit punt wordt geïllustreerd in de case studie over GMO's en in de case studie over mobiele telefonie.

Hoe dit concept van narratieve autonomie uitwerkt in de praktijk wordt duidelijk in de case studies. De eerste case studie, over het handelsconflict tussen de Verenigde Staten en Europe over de import van GMO's laat zien waarom het belangrijk is om diversiteit ten aanzien van risicopercepties te respecteren. De tweede case studie, over de vaccinatie van kinderen, illustreert hoe beperkingen opgelegd kunnen en moeten worden aan deze diversiteit aan perspectieven. De analyse van de laatste case studie over het debat over de vermeende risico's van mobiele telefonie integreert alle elementen van narratieve autonomie. Het laat zien hoe belangrijk het concept van identiteit is voor het begrijpen en evalueren van debatten over de aanvaardbaarheid van technologische risico's.



## About the author

Lotte Asveld obtained a masters degree in Cultural Sciences from the University of Maastricht, before starting her PhD-research at Delft University of Technology in September 2002. She is currently employed as a senior-researcher at the Rathenau Institute in The Hague, where she initiates research and organizes debates on the evaluation of technological developments. She is married to Donald Pols and together they have a son, Sieger.

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# Simon Stevin (1548-1620)

'Wonder en is gheen Wonder'

This series in the philosophy of technology is named after the Dutch / Flemish natural philosopher, scientist and engineer Simon Stevin. He was an extraordinary versatile person. He published, among other things, on arithmetic, accounting, geometry, mechanics, hydrostatics, astronomy, theory of measurement, civil engineering, the theory of music, and civil citizenship. He wrote the very first treatise on logic in Dutch, which he considered to be a superior language for scientific purposes. The relation between theory and practice is a main topic in his work. In addition to his theoretical publications, he held a large number of patents, and was actively involved as an engineer in the building of windmills, harbours, and fortifications for the Dutch prince Maurits. He is famous for having constructed large sailing carriages.

Little is known about his personal life. He was probably born in 1548 in Bruges (Flanders) and went to Leiden in 1581, where he took up his studies at the university two years later. His work was published between 1581 and 1617. He was an early defender of the Copernican worldview, which did not make him popular in religious circles. He died in 1620, but the exact date and the place of his burial are unknown. Philosophically he was a pragmatic rationalist for whom every phenomenon, however mysterious, ultimately had a scientific explanation. Hence his dictum 'Wonder is no Wonder', which he used on the cover of several of his own books.



Technological developments can undermine the autonomy of people. Autonomy is one's ability to make and act upon decisions according to one's own moral framework. Respect for autonomy dictates that risks should not be imposed on people without their consent. Technological developments can bring about risks that often confront people in ways beyond their control. This research deals with the question: How should autonomy be respected in the context of technological risks?

It is argued in this thesis that respect for autonomy requires amending current decision procedures on the acceptability of risks. These amendments should be based on a new concept of autonomy; narrative autonomy. Narrative self-understanding forms the core of this concept of autonomy. Respect for narrative autonomy requires that anyone who is concerned about risks associated with a technological development is allowed to influence the decision regarding the acceptability of those risks, provided that the arguments put forward are compatible with specific constraints. Why this is an important condition for decision procedures on risk and how this recommendation can be implemented is illustrated with case-studies on public debates concerning biotechnology, mobile phone technology and vaccination.

'Wonder en is  
gheen wonder'

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