

#### 4. Previous and future submissions

None

#### 5. Institutional setting

The project will be embedded in the research activities of

- the Department of Philosophy, Faculty of Behavioural Sciences, University of Twente, The Netherlands
- the Biomedical Technological Research Institute, University of Twente (BMTI), The Netherlands
- the Research School for Science, Technology and Modern Culture (WTMC), The Netherlands

#### 6. Period of Funding

1-9-2005 till 1-9-2006

#### 7. Composition of Research team

<i>Role</i>	<i>name</i>	<i>affiliation</i>	<i>discipline</i>
main applicant ; intended researcher	dr. T.E. Swierstra	Department of Philosophy, University of Twente	41000 Philosophy 52600 Political science
associate applicant, intended researcher	dr. M. Boenink	Department of Philosophy, University of Twente	41000 Philosophy 53903 Health education
intended researcher	dr. D. Stemerding	Department of Philosophy of Science and Technology, University of Twente	54002 Social issues in science and technology 11100 Biological sciences
intended researcher	prof.dr. M. Trappenburg	Utrecht School of Political and Organization Science, Erasmus Medical Centre Rotterdam	52600 Political science

#### 8. Thematic Classification

Programme Ethics of care and health:

1.1 Instruments for the early signalling, debate and judgment of moral problems in relation to technological developments

The project is also connected to:

Programme General, theoretical and methodological issues:

1.1 Empirical research and ethics

## 9. Description of Proposed Research

### Title

Developing scenarios of moral controversies concerning new biomedical technologies

### Introduction

New technologies often go accompanied by moral uneasiness. It is important to policy makers to spot such controversies at an early stage. That can help them prevent the development of technologies that are morally unacceptable to society. Ideally they might even be able to steer technology development in more desirable directions.

Several instruments exist to gear technology and social preferences to one another. In health care, cost-effectiveness-analysis (CEA), medical technology assessment (MTA) and scenario studies in particular are used. However, CEA's apply a rather limited, economic perspective to technology and neglect issues of distribution. MTA does focus on broader social consequences of new technologies, but can only be conducted when those technologies are already fairly developed. Therefore we want to focus on the third instrument: scenario studies. As exercises in *controlled speculation*, scenario studies try to anticipate the different technical and social development possibilities at an early stage. (Notten 2003, Schoonenboom 2003, Van Steenbergen & Bakker 2003)

However, scenarios can often be found lacking in three respects. (compare De Wilde 2000) First, being usually based on the assessments of technologists, the moral and social aspects are often inadequately argued for and presented rather haphazardly. A more systematic approach is called for. Moreover, scenarios tend to sketch homogeneous situations, devoid of disputes and controversies. Instead, scenario studies should focus on plausible controversies. Finally and most fundamentally, scenario studies often treat moral beliefs as independent variables without context, as if these would be immune to technological influences. Instead, they should explore the *mutual and dynamic interaction of technology and morality*.

As a consequence, policy makers currently find themselves in permanent danger of lagging behind techno-ethical developments. It is clear that a methodological approach to the development of ethico-technical scenarios would be highly relevant to policy makers. Such scenarios would enable them to anticipate the mutual interaction of technology and morality, and thus to contribute to creative solutions to plausible controversies.

### Goal

To develop a theoretical framework for the systematic exploration of potential moral controversies concerning new biomedical technologies, which is able to:

1. signal potential moral controversies at an early stage of technology development; and in doing so
2. to do justice to the mutual interaction of technology and morality, that is, to perceive both as mutually dependent variables.

### Theoretical environment and state of the art

The proposed research combines insights and methods from ethics, scenario studies, the philosophy of technology and science and technology studies.

Classical philosophy of technology concentrated on describing how instrumental reason and the technological imperative alienated Man from his essence, resulting in the reversal of the 'natural' hierarchy between subject and object and the perversion of morality. (Achterhuis 1992) This classical approach is nowadays generally rejected as being aprioristic, essentialist, ill informed about the complexities of concrete technologies and generally

technophobic. Recent philosophy of technology concentrates on particular technologies, studying the interaction between technology and society at the levels of worldview, anthropology, political theory etc. (Feenberg 1999) Sociologists of technology have also amply documented how technical and social factors influence each other (Brown et al. 2000, 2004, Sørensen & Williams 2002, Rip & Kemp 1998, Schot 1998-2002).

However, none of these parties have developed methods to systematically study the dynamic interplay between technological and moral change. This lack is probably due to the fact that such an enterprise would need the combined skills of philosophy of technology, science and technology studies and ethics. Ethicists have extensively debated (more often than not with a weary eye) the consequences of specific technologies or have developed proposals for interactive, deliberative forms of TA. (Reuzel et al. 2001) But they often fail to analyze the morality/technology interactions, lacking the necessary empirical knowledge of the dynamics of technology development. Furthermore, the still dominant focus on foundations and universality leaves ethicists generally ill equipped to deal with the dynamic character of morality in our technological culture. (Swierstra et.al 2002, Swierstra 2003; Van der Burg 2003)

In our research group we combine the necessary skills. Basing ourselves on comparative historical and sociological research and applying moral theory, we will try to identify levels and patterns in the relationship between technology and morality. These will then be worked into a heuristic framework for studying historical and contemporary technology/morality interactions and for developing scenarios anticipating such interactions.

It is clear that the proposed research will be highly innovative from a scientific/philosophical point of view. It will significantly deepen our understanding of the role of morality and ethics in the rapidly changing environment we call a technological culture. The research will contribute to a self-reflexive ethics of technology that explicitly acknowledges the possibility of moral change and dynamics. As philosophical resources, we will draw on philosophical pragmatism (Keulartz et al. 2002, Johnson 1993, Lekan 2003, Fesmire 2003) and so called 'empirical philosophy' (Mol 2000, Swierstra 2002). Both traditions are anti-foundationalist and pride themselves in nursing a sensibility for the transient and situated. Moral concepts, norms and values are understood as answers to practical problems that will change when the problems change.

### **Outline of the proposed framework**

Plausible scenarios of the mutual interaction of a specific technology and morality should take into account at least the four following aspects: the *ethical dimensions* of this interaction, the *robustness/solidity* of the norms and values that are mobilised, the *trends and path dependencies* in the development of norms and values, and the *recurring patterns* in the perception of new technologies.

#### *1. Ethical dimensions*

A new technology causes moral controversy when it disturbs established moral routines and compromises. To determine whether such disturbance is to be expected, a systematic exploration of what this new technology will do on four dimensions is needed. New technology a) enables new activities and blocks former ones, creating new (im)possibilities (dimension of prudence); it b) rearranges existing constellations of rights, obligations and responsibilities (as 'ought implies can') (dimension of rule ethics); it also influences c) existing distributions of costs and benefits as well and the common application of distributional criteria like 'desert' or 'need' (dimension of justice); and finally it may d) profoundly influence our identity and views of the good life (dimension of life-ethics). Exploring how a new technology affects these (interrelated) dimensions gives one an overview of potential subjects for future controversy. (Swierstra 2003)

## 2. Robustness

The next step is to judge the robustness of existing moral routines and to estimate their resistance to the pressure for change produced by the new technology. (Swierstra 2004b) A macro, meso and micro level may be distinguished here. The macro level is characterised by very general principles that have proven their usefulness over long periods of time and in many different situations. These principles have shown to be highly ‘transportable’: they have disengaged themselves from their original ‘context of invention’. The meso level is characterised by applications of these principles which are more specific to time and context. For example, as a result of processes of democratisation and the breakdown of traditional religious and social barriers in the 1960s and 70s, the principle of autonomy in the Netherlands is often interpreted as freedom of choice and is contrasted with paternalism, thus blocking alternative interpretations. (Swierstra 2004b) The micro level is characterised by solutions specifically designed for particular problems, for example the rulings of Medical Review Boards for medical experiments with human subjects.

## 3. Trends and path dependencies

Differences in robustness have a temporal dimension as well. (Miller & Broady 2001, Trappenburg 2003) Developments at the macro level, like processes of individualization and secularization, or the democratization of moral authority, are slow and hard to influence. The relationship between norms, values and specific problems is more direct at the meso level. Here changes will be observed if the context of the problem is changed by the introduction of a new technology. Thus, the general principle that the innocent deserve protection may be questioned when ‘superfluous embryo’s’, created in the course of IVF, enter the debate. At this level, path dependencies may be shown: established ethical solutions to old problems supply the framework for solutions to new problems. Applications of principles and norms to specific problems of action – the micro level – are very flexible, and thus may serve as a breeding ground for new insights and questions which may in time move up to meso- and macro levels.

## 4. Patterns in perception

The way stakeholders will perceive new technologies may be anticipated by exploring the probability that often recurring patterns in the perception of new technologies will prevail. At least three such patterns may be distinguished: the new technology is thought to be similar to an established one and therefore not morally controversial (the *precedent* view); it is supposed to lead to moral decline (the *slippery slope* view); or it is supposed to lead to a new morality (the *habituation* view). (Swierstra et al. 2002) These fundamental patterns in the way new technologies are perceived structure the moral controversies about these technologies. A question for further research is whether these patterns can be linked to existing groups of actors (scientists, patients, religious groups, industry) and whether different or more specific patterns may be discerned within the biomedical field.

Our hypothesis is that the exploration of these four aspects will enable us - if more or less clear ideas about what will be technologically feasible exist - to plausibly predict future moral controversies in the context of newly invented technologies.

## Design of the research and its projects

The framework outlined above will be tested and expanded in three projects, each exploring one domain of biomedical technology: farmaco-medicine (project 1), substitution medicine (project 2) and preventive medicine (project 3). In each project a historical case study will be matched with controlled speculation about the moral controversies that may be provoked by related technologies in the near future. This results in the following projects and cases:

### 1. farmaco-medicine

history and present: drugs research on human subjects (1a: Swierstra)

(near) future: drug delivery systems on nano-scale (1b: Boenink)

## 2. substitution medicine:

history and present: organ donation (2a: Trappenburg)

(near) future: tissue engineering (2b: Swierstra)

## 3. preventive medicine

history and present: population screening for breast cancer (3a: Boenink)

(near) future: genetic screening for multifactorial predispositions (3b: Stemerding)

This design will enable a cross-fertilization between historical case studies and scenarios for the near future, as well as the continuous refining and testing of our proposed framework. The technologies chosen ensure that a variety of morality/technology interactions will be studied.

Building on the results of the three projects, a general framework for writing technological scenarios will be developed. To this end the researchers will regularly meet and exchange findings. The responsibility for this synthesising project rests with the two main researchers.

Because of the innovative character of this type of analysis, good research models are lacking. For this reason we have decided for senior researchers who already possess intimate knowledge of the fields to be studied. This will enable them to concentrate their intellectual efforts on developing tools to study morality/technology interactions.

### **Project 1: Farmaco-medicine**

In this project, we first want to focus on the history of the moral controversy surrounding the testing of drugs on human subjects. (Realize that drugs themselves are a form of medical technology.) Taking the patterns discovered in that controversy as our cue, we proceed then to develop one or more scenarios to describe the controversies that will probably accompany the new technological practice of delivering drugs by use of nanotechnology. Here we can only roughly indicate how our four methodological principles will provide us with a heuristics for both reconstructing the past and for speculating about the future. The aim of the research project is to refine and add to this heuristics.

If new technologies provoke moral controversies, two focal points can usually be discerned: the first is constituted by the moral problems provoked by the *development* of the nascent technology (its effectiveness, safety, efficiency); the second is constituted by the *consequences* of the matured technology for individual users, their environment and society as a whole. (Swierstra 2002) In this controversy the first focal point is dominant. Most countries have by now developed procedures and arrangements to monitor the potential moral problems associated with drugs development. However, this stability may be disrupted by new technological developments like nanotechnology.

The 19<sup>th</sup> century introduced experimental science into medicine. Uncertainty on the *prudential level* (is this drug effective?) could ultimately be reduced only by testing a new drug on human beings. This implied burdens and risks for the patients or healthy subjects involved. Doctors turning into experimental scientists destabilised the existing Hippocratic moral consensus. Heated controversies in the dimension of *rule-ethics* were the result. Those stressing collective well being sharply conflicted with those stressing (and inventing) individual rights of the patients. The popularity of these positions traded places several times, partly due to external circumstances like wars and emancipation. In the dimension of *life-ethics*, the discussion has left us with a dominant *identity* of the test-person as a potential victim, to be protected against the overwhelming power of the scientific/medical/pharmaceutical industrial complex.

The historical analysis will show how elements in the moral environment of an issue can be differentiated according to their robustness. The general principles on the macro level are fairly robust. As a consequence, controversies concentrated on the meso-level. Two examples: was it more important to not harm the collective or the individual? Or: should the principle of autonomy apply to the patient in her/his relation to the doctor? In the end, stabilisation on the meso level led to the institution of ethical committees, and a relocation of controversies to the micro level.

Especially interesting are the *exemplars* that provide a model for new solutions to new problems: the atrocities of the nazi-doctors still guide much of our thinking on drugs testing. Path dependencies like this can help explain why the debate took certain turns, neglecting other viable moral possibilities. An alternative option is to treat the patient not as victim but as a citizen who bears responsibility for the common good. (Swierstra 2004a) Another possibility is shown by AIDS-patients who claimed a right to be a test subject for an experimental drug. (Epstein 1996)

Path-dependencies can be im- and explicit. In the first case we speak of ‘exemplary situations’ (Nauta 1984, Mol 2000, Swierstra 2002a); in the second case a path dependency takes the form of the argument of *precedent*. This is one of the argumentative patterns that are typical of deliberations on new technologies. For example: drafting for the army provided a precedent for sacrificing individuals to the national interest. (Latour 1993) Likewise, testing on humans has been denounced as an only seemingly benevolent first step on the *slippery slope* leading to an instrumentalisation and objectivation of mankind.

How exactly will this historical reconstruction help in developing plausible scenarios for the use of nanotechnology in drugs delivery? At this stage, only a few tentative hypotheses are possible.

Drug delivery systems on nanoscale are developed to prevent the degradation of drugs before they reach their target. (Van Est et al. 2004) If they simply operated in the domain of *prudence*, enhancing the effectiveness and reducing potential side-effects of existing drugs, they would not provoke new moral questions. Public controversy would then be unlikely and current means and procedures would be sufficiently robust and fitting to ensure a well considered judgement.

However, ‘nano-drugs’ probably will challenge accepted ways of dealing with experimental drugs leading to debates in the domain of *rule-ethics* and *justice*. (van Est et al. 2004, Baumgartner 2003) First, are they drugs or medical devices/implants? In current regulations this distinction is important. Whether experiments with nano-drugs should be subjected to the (usually more stringent) regulations of drugs, or to the regulations of new devices and implants, may become a matter of debate, in which both practical and moral issues are at stake.

Second, the behaviour of particles on a nanoscale seems to be governed by completely different laws than the behaviour of the same chemical substances on a more traditional scale. This raises fundamental difficulties in predicting the potential (side-)effects of ‘nano-drugs’. This may force us to reconsider accepted criteria and procedures for deciding whether it is morally legitimate to test ‘nano-drugs’ on human beings.

Furthermore, seen from the perspective of justice, the development of ‘nano-drugs’ might put the consequences of the use of drugs on the agenda again. If connected to developments in genomics, nano-drugs may be developed for specific individuals. Tailor-made drugs, however, will be far more expensive in development and use than generic drugs, so at least the financial consequences may become subject of public debate again. (Mnyusiwalla 2003)

Thus, presuppositions underlying the current practice of dealing with new drugs may be challenged by bio-nanotechnology. Whether the existing moral framework will prove to be robust enough to create path dependency, remains of course to be seen in the case study proposed here.

## **Project 2: Substitution medicine**

The second project consists of the testing and further developing our theoretical framework by applying it to the controversies dealing with instances of substitution medicine. The first case study concentrates on the historical reconstruction of the interaction of morality and law with the development of transplantation technology. The second case study on tissue engineering will build on the first one, by extrapolating into the future the insights in the interaction between morality and transplantation technology.

The moral-political debate on post mortem organ donation in the Netherlands was dominated by a pattern of *path dependency*. Back in the nineteen seventies when the progress of transplantation technology created new possibilities, the moral question was raised whether one could use organs taken from dead bodies in order to cure other people. Some argued that this technology would lead us onto a *slippery slope* towards the instrumentalization and degradation of the human body. Most however applied a form of *precedent* or analogy argument: we should deal with post mortem transplantation similar to the way we dealt with post mortem section. One could use organs from the deceased provided they (or their next of kin on their behalf) had given their permission. This answer was generally accepted because it agreed with *robust* ideas on the macro level about autonomy and self-determination.

During the nineteen eighties a shortage of donor organs occurred. Many important actors in the health care policy network bent over backwards to argue that we ought to change the existing moral rules. They advocated a so-called no objection system: dead people could be used for post mortem donation unless they had registered an objection. In the end this lobby was dismissed. The present law on organ transplants (adopted in 1996) is firmly based on the old permission dogma.

This part of the debate has been analysed by Trappenburg (1993) and Den Hartogh (2003), but more recent developments in the debate are as yet relatively under-analyzed (cf. however Zwart & Hoffer 1998) Some of these can be characterized as *life-ethical* reactions to this technological practice, e.g. the emotional aspects of a transplantation procedure. The line between life and death was redefined to match the new needs of the transplantation technology. As a consequence, nowadays people hear that their beloved relative is brain dead and then have to think about a donation request. If they agree, they have to leave their beloved with the doctors while he or she is still warm and breathing. Other aspects are primarily *rule ethical* in character. People who donate organs are not supposed to know the recipients of the donation. Nor can they specify a preference for certain kinds of donors rather than others (e.g. to women or black people, or not to alcoholics). This is a remarkable contrast with the moral debate over 'living donations'. People who want to donate e.g. bone marrow during their lifetime, can only donate to known relatives. Why did the debate on post mortem donation end in very impersonal rules, donation following from a presumed universal altruism, whereas the debate on living donors ended up with extremely personalized rules, donation depending on family love? Is it thinkable that the two regulatory regimes will develop and become more similar? In certain hospitals living donors can consent to donate cross-wise – a typical example of a solution on the *microlevel* which might in time be promoted into a more general policy on the *mesolevel*. Why is donating body material during one's lifetime not framed in terms of distributive justice? And why did some themes come up early in the debate, and

others only at a later stage? To what extent do these ethical differences hinge on the differences between the technological practices involved?

In the second part of this project we will investigate to what extent established practices of organ transplantation and emerging practices of tissue engineering share morally relevant features, and where they part. (Van 't Hoog 2001) Is it plausible that the moral framework around the new technology will be derived from the existing one (*path dependency*) or will participants in the debate succeed in putting new moral questions on the agenda? Those who claim that there is nothing new under the sun (*precedent view*) may clash with others who claim that tissue engineering will set us on the path to moral degeneracy (*slippery slope*), who in turn might face opposition from those who are convinced that we will grow accustomed to the idea of having spare body parts (*habituation*).

Part of the debate will probably be *prudential* in nature: will the new technology have perverse effects, e.g. lead to more unhealthy lifestyles? The main difference however, and therefore most probable focus for future controversies, is between *engineering* and *donating* body material. Stem cells will be used on an expanding scale: the patient no longer *receives* from another human being, (s)he *takes* from a pre-embryo. This –disputed - inclusion of new stakeholders will lead to *life-ethical* controversies about what makes a human truly human, about the objectivation and instrumentalization of innocent others. And of one's one body, for which spare parts can now be made. Will tissue engineering prove to be a step towards immortality, and if so: how desirable is that? The new technology embodies values of autarky and independence, as opposed to the values of sharing and (inter)dependence inherent to organ transplantation. Tissue engineering will help to undermine the distinction between cure and enhancement, and lead to *rule-ethical* controversies about whether/when one has a right to new organs. And does justice require that the collective should pay for replacements? How desirable is it that the gap between rich and poor might become even more directly inscribed into the body? We will explore these questions, always asking ourselves how *robust* the moral framework that developed around organ transplantation will probably be in this new socio-technological context.

### **Project 3: Preventive medicine**

Collective efforts to prevent disease and preserve health necessarily rely on technologies diagnosing disease at an early, pre-symptomatic stage or identifying people 'at risk' for specific diseases. The 20<sup>th</sup> century has shown rapid developments in both domains, paving the way for population screening programmes that offer possibilities for risk-identification or early diagnosis to people who have no complaints and probably would not have asked for diagnosis themselves. In the Netherlands, population screening programs initially focused on communicable, infectious disease (tuberculosis). In the last quarter of the 20<sup>th</sup> century population screening initiatives were directed to non-communicable, age- (and gender)related disease (breast and cervical cancer) and today we see a growing interest in population screening of familial, genetic disorders. Whether such programs are desirable and under what conditions, has been subject of continual debate.

In this project we will use the proposed theoretical framework to study the question how developments in population screening and developments in the moral field have been shaping each other in the past, and will be shaping each other in the future. In the first part of this project we will study how mammographic screening was introduced and accepted in the Netherlands between 1970 and 2000. This was also the period in which a moral consensus emerged on the principles that should guide population screening programmes, principles that

were finally laid down in a new law on population screening (WBO, dating from 1996). In the second part of this project we will explore the question how established principles and perceptions of population screening in the moral domain, and emerging prospects and initiatives in the field of genetic screening may be going to affect each other in the near future.

Mammographic screening was introduced on a national scale in the Netherlands only after an extensive period of research and scientific and political discussion in the 1970's and 80's (Dietvorst 2003). In the discussion *prudential considerations* were paramount. Would screening really enhance prognosis and reduce mortality rates? Which technology, which interval and which group of participants would produce the highest benefit? Potentially *life ethical* issues like the importance of health and prevention in one's view of the good life were translated into prudential terms, for example in weighing the potential benefits of screening against the (emotional) costs of false positive results. *Rule ethical* issues were touched on, but only fleetingly. The supposition that participation would be based on individual choice apparently did not need extensive argumentation.

The largely *prudential* and to a lesser extent *rule ethical* orientation of the moral debates on mammographic screening raises interesting questions about how, in the Netherlands, these debates and the organisation of the screening practice were related to international discussions about the principles of population screening in general, issuing in the 10 criteria formulated by Wilson & Jungner (1968). In our study we use the four ethical elements of our theoretical framework to trace the various moral considerations and perceptions that have shaped debates about population screening. Thus, we want to show how the debates about mammographic screening and about the principles of population screening have converged into a relatively *robust* normative framework in terms of which the acceptability of population screening is discussed.

As a result of rapid developments in human genome research, geneticists and public health agencies have begun examining how advances in human genetics can be used to prevent disease and improve health of the population (Khoury *et al.* 2000 and 2003, Cornel 2003). In the Netherlands, discussions about the prospects of genetic screening explicitly refer to the criteria included in the Population Screening Act as a basis for decision-making about the introduction of new screening initiatives. At the same time, however, these criteria are also subject of debate as a result of developments and expectations in the field of genetic screening (Gezondheidsraad 1994, Khoury *et al.* 2000 en 2003). So, we can assume that future developments in genetic screening will be shaped by *path dependency* in the moral domain, but we may also expect tensions and controversies concerning the appropriateness of established moral conceptions. On the basis of these suppositions, we will endeavor in this part of the project at controlled speculation about future interactions between technology and morality, focusing on emerging expectations about screening of multi-factorial genetic predispositions for common diseases (Leschot *et al.* 2004). One important consideration that may guide our speculations is that identification of genetic predispositions not only entails information about individuals participating in a screening program, but is potentially relevant for relatives as well. Thus, established *rule ethical* notions of informed consent and confidentiality may become contested in dealing with genetic risk information that also has potential relevance for others than those participating in a screening program (Rabino 2003). In the light of the uncertainties inherent to risk information about multi-factorial predispositions, we may further expect growing moral debate about the issues of predictive value and ensuing interventions. An interesting question is whether these issues will be debated in terms of *prudence*, or in terms of *life ethics*, that is, in terms of the ability and willingness of individuals to deal with uncertainties (Swierstra 2004c). Moreover, by creating

new risk groups, emerging practices of screening for genetic predispositions will also provoke debates about priorities in public health policy and thus concern issues of *justice* and solidarity (Halliday *et al.* 2004, Horstman 2004). In this way we want to use our theoretical framework as a basis for the construction of scenarios, including also different perceptions of future developments, either in terms of a slippery slope of ‘geneticization’, or in terms of more optimistic, precedent or habituation views, in which genetics is perceived as contributing to longstanding or new public health values.

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- Swierstra, T., M.Korthals en J. Keulartz (2002), ‘You only live twice. Ethische tekorten in het omgaan met genomics’. [paper geschreven in het kader van het NWO Genomics programma; uitgekomen op CD-rom]
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- Trappenburg, M., ‘Darwin in de medische ethiek’ (2003), in: M. Adams, J. Griffiths en G. den Hartogh (red.) *Euthanasie. Nieuwe knelpunten in een voortgezette discussie*, Kok, Kampen, pp. 237-254.
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Wilson, J.M.G. & G. Jungner (1968), *Principles and practice of screening for disease*. WHO Public Health Papers no. 34, Geneva, World Health Organization.  
Zwart, H.A.E. en C.B.M. Hoffer (1998), *Orgaandonatie en lichamelijke integriteit: een analyse van christelijke, liberale en islamitische interpretaties*, Damon, Nijmegen.

#### *10. Word count*

general description: 1835 words

project 1: 977 words

project 2: 973 words

project 3: 945 words

#### *11. International perspective*

The proposed research is interdisciplinary, because it combines co-evolution studies in STS, scenario studies, work on pragmatism and moral imagination in philosophy and ethics, and philosophy and ethics of technology. This combination makes the proposed research unique, in the Netherlands as well as internationally. However, the researchers have extensive international contacts on one or more of these disciplinary domains: Prof. Ruth Chadwick (director CESAGEN, Lancaster University; bioethics, ethics of technology), Prof. Carl Mitcham (Colorado School of Mines; philosophy of technology), Prof. Martha Nussbaum (University of Chicago; moral imagination), Prof. Paul Thompson (Michigan State University; philosophy of technology, pragmatism), Prof. Andrew Webster (University of York; science and technology studies). We will consult these colleagues during the project, invite them (and others) to the final international workshop planned for August 2006, and some of them will be asked to contribute to the monograph.

#### *12. Work programme*

September 2005	Start up workshop, preparation of methodology
October –November 2005	Historical case studies (project 1a, 2a and 3a)
December 2005	Drafts of publications on historical articles
January –April 2006	Actual case studies and comparative research (project 1b, 2b and 3b)
May 2006	Drafts of publications on both case studies
June 2006	Draft of working paper
July 2006	Preparation of monograph
August 2006	Two workshops on working paper
(September – December 2006)	Preparation of final monograph)

#### *13. Planned deliverables and knowledge dissemination*

##### *planned deliverables:*

- three scientific articles (in English) concerning the historical case studies and their relevance for developing a framework for scenario writing
- three scientific articles (in English) in which the results from the historical case studies are extrapolated into the actual scenario studies and the heuristic power of the framework is tested
- a synthesizing working paper (in English) presenting a refined framework for scenario development based on the six case studies, which will be the subject of two final workshops (see below). Depending on the reactions, this paper will then be submitted for publication immediately or after revision.

We also intend to publish a final monograph (in English) in which the case studies as well as the revised general framework for scenario development are presented. Since such a monograph in our view should be more than just a collection of articles published elsewhere,

and the project period is limited to 1 year only, the final version of the monograph will be prepared in the months following the end of the project, thus strictly falling outside the period to be funded by NWO.

#### *dissemination of results*

The research intends to develop a framework for writing techno-ethical scenarios that is relevant for policy makers as well as researchers. Therefore, at the beginning of the project an advisory board will be installed consisting of policy makers and representatives of organizations active in scenario studies and public debate concerning technology (Rathenau, STT, STG, VWS). This board will serve, together with our international academic colleagues, as a sounding board for the feasibility of the framework in development. At the start of the project, moreover, a workshop will be organised in which the problems will be explored together with members of the advisory board and other (Dutch) representatives of the target group.

At the end of the project, two workshops will be organised to present and discuss the results, a national one with Dutch policy makers and scenario writers, and an international one with academic researchers from the field. In both, the final working paper (see above) will be the subject of discussion. The policy makers will be asked to discuss the working paper from a practical point of view. The academic researchers will be invited to discuss it from a theoretical point of view, and to add their own thoughts on how to anticipate the interplay between morality and technology. The reactions will be used to rewrite the working paper. This will then serve as the basis for the final monograph collecting the case studies, the scenarios and the contributions of the academic researchers.

#### *14. Short Curriculum Vitae principal applicant*

Dr Tsjalling Swierstra (Zutphen 1960).

##### educational history

1978: final exam high school (Gymnasium)

1987: doctoral exam Philosophy, University of Amsterdam (*cum laude*)

1988: doctoral exam Political Sciences, University of Amsterdam (*cum laude*)

1998: doctoral dissertation in Philosophy, University of Groningen (title dissertation: *De sofocratische verleiding; over het ondemocratische karakter van een aantal moderne rationaliteitsconcepties (The sophocratic seduction: concerning the undemocratic character of several modern conceptions of rationality)*, Kok-Agora, Kampen)

##### work history

1987-1991: AIO (PhD student), University of Groningen, Department of Philosophy

1992-1996: Lecturer in philosophy, University of Groningen, Department of Philosophy

1996-now : associate professor in the Philosophy of Technology, University of Twente,

##### relevant activities

1987-1995: editor Dutch journal of philosophy *Krisis*

2000-present: research projects commissioned by the Rathenau Instituut::

in 2000: *Kloneren in de polder. Het maatschappelijk debat over kloneren in Nederland: februari 1997 – oktober 1999* (2000) (Research report 'Cloning in the polder: the social debate on cloning in the Netherlands, February 1997 – Oktober 1999)

in 2002 (with M. Kirejczyk and D. van Berkel): *Nieuwe voortplanting; het afscheid van de ooievaar. Sociaalhistorische en normatief politieke aspecten van de ontwikkeling van voortplantingstechnologie in Nederland* (New reproduction: a

farewell to the stork. Social-historical and normative political aspects of the development of reproduction technology in the Netherlands)

2002-present: editor Dutch journal of philosophy *Krisis*

2002-present: series editor Amsterdam University Press 'Vernieuwingen in de politieke theorie' (Innovations in political theory) (with prof.dr.I.de Haan)

2002-present: member of the national Commission on Biotechnology in Animals

2003-present: member of the Board of the Research School for Science, Technology and Modern Culture (WTMC)

#### research grants

- Rathenau Institute commission (2000): ethical analysis of the public debate on cloning in the Netherlands (Swierstra 2000)
- Rathenau Institute commission (2001): ethical analysis of the debate on new reproductive technologies (Kirejczek, van Berkel en Swierstra 2001)
- NWO grant (2000-2002): Pragmatism and Technology ethics (main applicant: Korthals. With: Keulartz, and Schermer)
- NWO-grant (2002): commission for an essay for the Social Component of Genomics Program (with Keulartz en Korthals)
- NWO-grant 2002-2004): The social component of genomics: the case of obesitas. (main applicant: Korthals. With: Van den Belt, Keulartz)

#### organized workshops on technology and ethics

- International WTMC/CSI-workshop 'The consequences of Science and Technology Studies for Political Theory and Ethics', Maastricht, 16-18 January 1998.
- WTMC-workshop 'Between fatalism and moralism', Enschede, 13 March 1998 (co-organized dr.J Jelsma)
- WTMC-workshop 'Ethics and Technology', Enschede, 30-31 January 2004 (with dr.P.Breij)
- WTMC-workshop 'Genomics & Politiek: Wetenschap en Technologie Studies en de vraag naar politieke zeggenschap in relatie tot technologie' ('Genomics and Politics: Science and technology Studies and the question of political voice in relation to technology', 19 & 20 March 2004, Hilversum (with dr.A.Nelis)

#### associate supervisor of PhD-students:

- M.Smits [doctoral degree 2002]
- L.Dubbeld [doctoral degree 2004]
- R.Struhkamp [doctoral degree 2004]
- G.Valkenburg [doctoral degree scheduled for 2008]

### *15. Literature*

#### a. Selection of publications by applicants

##### Swierstra:

(accepted manuscript) with J. Jelsma 'Responsibility without Moralism. Normativity in Techno-Scientific Design Practice', *Technology and Human Values*

(2004c): 'Van rechtvaardigheid naar het goede leven: genetica en genomics in de dagbladen' [From justice to the good life: genetics and genomics in the dailies], in: N.J.Leschot en D.L.Willems (red) *De genetische ontrafeling van veel voorkomende aandoeningen*, Elsevier Gezondheidszorg, Maarsen

(2004b) *Slachtoffer of Burger? een essay over het nader gebruik van lichaamsmateriaal ten behoeve van genomics onderzoek*. [Victim or Citizen: an essay on the re-use of body materials for genomics research] [Preadvies uitgebracht t.b.v. de jaarvergadering van de Nederlandse Vereniging voor Bioethiek op 30 september 2004/]: NVBE, Amsterdam

(2004a) with J. Keulartz, M. Schermer, M. Korthals, 'Ethics in a Technological Culture. A Programmatic Proposal for a Pragmatist Approach'. In: *Science, Technology and Human Values*, Vol.29 No. 1, 3-29

(2003) 'De wisselwerking tussen ethiek en technologie. Naar een moderne technologie-ethiek'. [The mutual interaction between morality and technology. Towards a modern ethics of technology] In: Devisch, I. en G. Verschraegen (red.)

(2003), *De verleiding van de ethiek. Over de plaats van morele argumenten in de huidige maatschappij*. Boom, Amsterdam, 154-171

(2002b) 'Moral vocabularies and public debate: the cases of cloning and new reproductive technologies'. In: Keulartz, J., M. Korthals, M. Schermer en T. Swierstra (eds.) (2002) *Pragmatist Ethics for a Technological Culture*. Kluwer Academic Press, Deventer, 223-240

(2002a), 'Ethiek op zijn plaats zetten. Normatieve ethiek als empirische filosofie' [Putting ethics in its place. Normative ethics as empirical philosophy]. *Krisis*, (3) 3, 18-38

#### Boenink:

(2004) 'Genetische diagnostiek voor erfelijke borstkanker. Verplaatsing van onzekerheid en verantwoordelijkheid [Genetic diagnostics for hereditary breast cancer. Relocation of uncertainty and responsibility]'. In: G.H. de Vries & K. Horstman, *Genetica van laboratorium naar samenleving. De ongekende praktijk van voorspellende genetische testen*. Amsterdam, Aksant

(2003) 'Gezond vertrouwen. Over de rol van vertrouwen in het bevolkingsonderzoek naar borstkanker [Healthy trust. On the role of trust in the population screening programme for breast cancer]'. In: *Krisis, tijdschrift voor empirische filosofie* 4 (2003) 1, pp. 53-74.

(2000) *Boekenwijsheid. Filosofie, literatuur en politieke oordeelsvorming [Book knowledge. Philosophy, literature and political judgment]*. Dissertation, University of Amsterdam.

#### b. International literature

##### philosophy of technology

1. Feenberg, A. (1999) *Questioning Technology*, Routledge, London and New York
2. Mitcham, C (1983), *Philosophy and Technology*, New York, Free Press
3. Pott, J. van der (1985) *Die Bewertung des technologischen Fortschritts. Eine systematische Uebersicht der Theorien*, Assen/Maastricht, Van Gorcum

##### science and technology studies

4. Brown N, Rappert B, Webster A (eds) (2000), *Contested Futures. A sociology of prospective techno-science*, Ashgate
5. Rip A. & R. Kemp (1998), 'Technological Change', in: S. Rayner & E.L. Malone (eds), *Human Choice and Climate Change*, Columbus, Ohio: Battelle Press. Volume 2, 237-399

6. Sorensen KH & Williams R, (eds), *Shaping Technology, Guiding Policy: concepts, spaces and tools*, Edward Elgar

ethics:

7. Buchanan A. Brock D., Daniels N, Wikler D (2000), *From Chance to Choice*, Cambridge, Cambridge U.P.
8. Burg, W. van der (2003). 'Dynamic Ethics'. *The Journal of Value Inquiry*, 27, 13-34,.
9. Johnson, M. (1993), *Moral Imagination*, Chicago, University of Chicago Press
10. Keulartz, J., M. Korthals, M. Schermer en T. Swierstra (eds.) (2002) *Pragmatist Ethics for a Technological Culture*. Kluwer Academic Press, Deventer

### 16. Summary for non-specialists

Beleidsmaker moeten anticiperen op mogelijke morele controversies rondom nieuwe technologieën. Huidige toekomstscenario's schieten echter tekort omdat ze onvoldoende recht doen aan de dynamische wisselwerking tussen technische en morele ontwikkeling. Doel van het onderzoek is het (verder) ontwikkelen van een theoretisch raamwerk voor het ontwerpen van betere ethico-technische scenario's. In drie deelprojecten (over het testen van geneesmiddelen, over vervangingsgeneeskunde en over voorspellende geneeskunde) onderzoeken we eerst een morele controversie rondom een nieuwe medische technologie uit het verleden, om vervolgens de daarin bloot gelegde patronen te gebruiken voor een toekomstscenario over een verwante, maar nog niet gerealiseerde, medische technologie.

Ons theoretische raamwerk bevat voorlopig vier elementen:

- 1) de praktisch-morele veranderingen tengevolge van een nieuwe technologie:: wat wordt (on)mogelijk? hoe veranderen bestaande rechten, plichten en verantwoordelijkheden? wordt de verdeling van schaarse goederen (on)rechtvaardiger? wat zijn de gevolgen voor vigerende opvattingen over het goede leven?
- 2) hoe robuust zijn de verschillende morele elementen rondom de nieuwe technologie? Zullen ze de techniek mede vorm kunnen geven, of is de omgekeerde beïnvloeding waarschijnlijker?
- 3) liggen bepaalde padafhankelijkheden in de discussie voor de hand, waarbij oude oplossingen worden toegepast op nieuwe, maar verwante problemen?
- 4) in publieke debatten over nieuwe technologieën zijn een drietal argumentatiepatronen aanwijsbaar: het *precedent* argument, het *hellende vlak* argument en het *gewinnings*argument. Het is plausibel dat deze ook toekomstige controversen zullen structureren.

Met dit theoretische raamwerk worden zowel controversen uit het verleden gereconstrueerd, als scenario's ontworpen die beleidsmakers helpen zich voor te bereiden op toekomstige morele controversen rondom nieuwe technologieën.

### 17. Research budget

#### Personnel

- replacement subsidy Swierstra 0,5 fte x 1 year	27.146
- replacement subsidy Boenink 0, 5 fte x 1 year	27.146
- replacement subsidy Trappenburg 0, 2 fte x 1 year	10.858
- replacement subsidy Stemerding 0, 2 fte x 1 year	10.858
totals	76.008

#### Material

internationalization:	
- congress fees and travel expenses	8.000
dissemination	
- editing of English texts by native speaker	5.000
- organization of 3 workshops	18.000
 Total amount	 107.800