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Exploring the interaction between technology and morality in the field of genetic susceptibility testing: A scenario study

Dirk Stemerding [a,*], Tsjalling Swierstra [b], Marianne Boenink [b]

[a] Department of Science, Technology and Policy Studies, University of Twente, P.O. Box 217, 7500 AE Enschede, The Netherlands
[b] Department of Philosophy, University of Twente, P.O. Box 217, 7500 AE Enschede, The Netherlands

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ABSTRACT

With the rise of genomics promises and concerns have emerged about future possibilities for screening of genetic susceptibilities to common diseases in the population. In this article we start from the assumption that for a better understanding of the future ethical implications of genetic susceptibility screening we need to address the interaction between technological and moral developments in society. We introduce a techno-ethical scenario approach and show how it may help us to explore more systematically potential future interactions between technological and moral developments in the field of genetic susceptibility screening. The first step is a historical account of population screening, focussing on the ways in which emerging practices of (genetic) screening have been mediated by an evolving moral landscape in our society. Based on this history we present a techno-ethical scenario of the future, showing how technological developments may shape conditions in our society in which the introduction and use of genetic susceptibility tests more and more become a matter of private decisions, reinforcing claims to individual self-determination as a deeply rooted value in the moral landscape of our society.

1. Introduction

In a highly informative article, published fifteen years ago, Davison et al. addressed predictive genetic testing for susceptibility to common chronic diseases as an important future topic of concern [1]. They noted how at the time many anticipated testing for genetic predispositions to a wide range of cancers, respiratory diseases and cardio-vascular disorders, as well as for other common physical and mental conditions such as diabetes, alcoholism and schizophrenia. The authors emphasized the need for a timely exploration of the social and ethical implications of this growing knowledge of genetic susceptibilities, because in a rapidly changing scientific field "technical knowledge may outstrip the development of the ethical, cultural and political infrastructure required to control it" (p. 341). Such an exploration, however, would not have to start from scratch. Past and current experiences in population screening for breast cancer and raised cholesterol levels already illustrated the potential impact of predictive susceptibility testing. Predictive genetic screening therefore would arrive in a "professional arena containing many pre-existing conceptual structures and debates" (p. 352).

Today, genetic testing has indeed been introduced for predispositions to breast cancer, colon cancer and hypercholesterolemia [2–4], but for a wide range of other common conditions genetic susceptibility testing has still to come. Yet, living in a time of genomics, the prospects of susceptibility testing are more actively debated than ever and great investments are made in the hope that earlier promises will materialise [5–10]. In the scientific literature *public health*

* Corresponding author. Tel.: +31 534893353/647268771.
E-mail addresses: d.stemerding@utwente.nl (D. Stemerding), t.e.swierstra@utwente.nl (T. Swierstra), m.boenink@utwente.nl (M. Boenink).

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genomics has been introduced as the endeavour to substitute the "one size fits all" paradigm in public health with personalized forms of medicine able to predict and prevent disease [11–13]. This hope, however, clearly remains controversial. Questions are being raised both about the complexity of interactions between genetic and environmental factors in common diseases, and about the social and ethical issues emerging from the translation of knowledge about individual genetic susceptibilities into public health interventions [14–23].

In this context of hopes and controversies, we take up again the challenge signified by the early contribution of Davison et al. We share their aim that one should prepare for the future by timely thinking through the potential social and ethical implications of genetic susceptibility testing. We also share their idea that previous moral debates constitute an important framework for future technological developments. But our approach is different from theirs in that they depict technology as potentially *outstripping* established ethical, cultural and political frameworks, suggesting that, faced by technological change, we should hold on to established moral frameworks. By contrast, we aim for a *symmetrical* and *dynamic* approach, which allows us to systematically explore the ways in which technological and moral developments may shape future society in a process of *interaction*. Our basic assumption is that a new technology in society often will create tensions, whereby on the one hand pre-existing practices and notions will shape the ways in which technology becomes embedded in society, and on the other hand, current infrastructures, practices and moral notions are challenged by the new technology. This assumption we have translated in a specific *techno-ethical scenario approach*, focussing on the tensions and interactions between technological and moral developments [24].[1]

In this article we show how this approach may be applied to past and future practices of genetic susceptibility testing. Our starting point is a discussion in Section 2 of recurrent *patterns of ethical argumentation* in debates about new and emerging science and technology, which may help us to anticipate, in a systematic way, future issues of moral debate [26]. Based on this discussion of the so-called NEST-ethics, we introduce the notion of a *moral landscape*, referring to those moral beliefs that that have a long history in our society and that as such may be mobilised, or indeed challenged, by actors striving for particular resolutions of moral controversies about new and emerging technologies [27,28]. In order to explore how new possibilities for genetic susceptibility testing might plausibly interact with established moral beliefs, we present in Section 3 a history of the relevant moral landscape in Dutch society. We show how, in debates about population screening, particular values have emerged as robust elements which will pre-structure future debates about genetic susceptibility testing. Based on this history, we finally present in Section 4 a future techno-ethical scenario, showing how the interaction between moral and technological developments might take shape in the context of emerging practices of genetic susceptibility testing. Our aim is not to offer an abstract judgement in terms of the most 'rational' solution of particular controversies, but to suggest a direction that might be considered plausible in the light of past and present, moral and technological developments. In our conclusion we discuss the relevance of our techno-ethical scenario approach for debates about future social and ethical implications of genetic susceptibility testing as a new and emerging technology.

2. How to learn from past ethical debates on new and emerging technologies?

2.1. NEST-ethics: a repertoire framing moral controversies

In their analysis of ethical debates raised by new and emerging technologies, Swierstra and Rip [26] have identified typical patterns of argumentation, and have shown how these patterns may be characterised in terms of arguments relating to the (un)desirable *consequences* of a technology (consequentialism); to the *rights*, *obligations and responsibilities* of those affected (deontology); to the *distribution* of costs and benefits (justice); and to the *good life* (virtue ethics). In this way, they have produced an inventory of recurrent types of arguments in ethical debates about new and emerging technologies, constituting a NEST-ethics that is available in late modern society as a repertoire framing future debates about new technologies.

So, in thinking about the social and ethical implications of genetic susceptibility testing, we may expect the repertoire of NEST-ethics to be reproduced in future debates about these implications. Imagine a debate raised by the tragic incident as described below.

A tragic incident:

> In the spring of the year 2012, a Dutch newspaper reports of a 62-year-old woman who committed suicide after having learnt about her significantly elevated genetic risk of Alzheimer's disease. Because of her family history, she had sent a drop of blood to a commercial provider of genetic tests, offering its services through the Internet. In the article, one of the daughters of the woman expresses her surprise and indignation that the provider of the test informed her mother about her individual risk status without any knowledge of her personal circumstances and without involvement of a health care professional who might have offered information and support.

[1] This article is based on a research project in which we took the interaction between technology and morality as a starting point in attempts to anticipate the social and ethical implications of new and emerging technologies. Genetic susceptiblity testing was one of our case studies. See Boenink et al. [25] for a case study focussing on the interaction between technology and morality in the field of bionanotechnology.

How to use NEST-ethics as a source of inspiration when imagining a public debate sparked off by such a newspaper report? Typically, NEST-ethical debates start with promises made by proponents of new technologies about particular advantages that a new technology may bring. But while these promises can enrol allies, they can also raise concerns, leading to consequentialist contestation, which will often take the form of discussions about the *ratio of benefits and costs* of a particular technology. Indeed, we can safely assume that the commercial supply of a growing number of genetic susceptibility tests will lead to debate in these terms. In this debate, critics may refer to well-established criteria for population screening, according to which benefits from screening are only to be expected when effective options are available to treat individuals at risk. Without such options, as in the case of the unfortunate woman, screening clearly may do harm. Thus, in terms of this consequentialist framework, (genetic) screening should only be introduced after a careful weighing of the advantages and disadvantages in a collective process of professional and political decision-making [29,30].

However, in debates about new and emerging technologies, we also find a deontological pattern of argumentation in terms of rights and obligations. Often, deontological principles are mobilised in support of new technologies, in terms of a moral obligation to further human progress or to help diminish suffering, or as *the right to choose freely* whether or not use a particular technology. Thus, the idea that professionals or the government should decide, on the basis of official guidelines, who can and cannot have access to options for genetic susceptibility testing is bound to be contested in terms of a well-established right to individual autonomy [29]. It may even be condemned as out-of-date paternalism, denying individuals the right to personal and potentially empowering genetic information that may help them to prepare for a devastating disease like Alzheimer's [31].

Finally, arguments focussing on justice or drawing on good life ethics will also recur in debates about new and emerging technologies in society. A typical argument relating to distributive justice is the *fear of a techno-divide*, a gap between haves and have-nots. In debates about genetic susceptibility testing, we may expect this argument to recur in a concern for increasing health care inequalities. As genetic susceptibility tests become more and more commercially available, the health care system may be put under increasing pressure by the rising demands of a growing group of healthy (and wealthy) consumers having acquired personal genetic information about future health risks. Another concern which we may expect to recur in any future debate about genetic susceptibility testing, is the emergence of a 'worry culture', a society of 'hypochondriacs', exemplified in a tragic way by the suicide in the newspaper report. In this fear we find expressed a particular framing of the 'good life', referring to *culturally shaped identities and aspirations*: who are we and who do we want to be?

2.2. The co-evolution of technology and morality: a multi-level perspective

The foregoing illustrates how the repertoire of NEST-ethics helps us to explore future moral controversies concerning genetic susceptibility testing. But, how to account for possible future interactions between technological and moral developments in this field? An important point of NEST-ethics is the *co-evolution* of technology and morality. Technological developments will not only be promoted or contested in terms of generally accepted moral principles, but may also provoke debates challenging established moral routines. To explore this interaction, it is helpful to consider NEST-ethics in terms of a multi-level perspective of socio-technical change in society [32–34].

We may start then from the observation that some moral principles in our society have a long and venerable past. They have proven their worth over and over again, in many different contexts, and thus constitute a moral *landscape* on the macro-level of our society. Examples of such highly robust and widely accepted principles are non-maleficence, benevolence and autonomy. Such principles are not immune to change, but we expect them to change only slowly. On the meso-level of institutionalised practices, we find particular concretizations of these abstract principles, constituting rules and procedures as moral *regimes* which relate to specific types of situations, as for example procedures for asking informed consent in order to protect the autonomy of patients. On the micro-level, concrete moral questions may arise from specific practices and circumstances, constituting *niches* in which moral rules and procedures are being debated and negotiated, for example in response to new technological developments.

From this multi-level perspective, NEST-ethics may be conceived as a repertoire that is highly entrenched in the moral landscape of our society and that as such is available in the form of forceful principles and arguments that can be drawn upon in concrete debates about new and emerging technologies. Thus, existing moral convictions and routines will shape the ways in which future technologies become embedded in society. At the same time however, the meaning of established moral beliefs and practices may also be questioned in these debates as a result of new practical possibilities opened up by future technologies. Such new practical possibilities will especially be encountered while a new technology is being introduced and taken up in particular niches. It is on this micro-level that novel moral questions arise which render established moral practices and routines problematic. Moral beliefs and practices may change because existing moral principles are interpreted in radically different ways or are weighed differently. Such changes may be local and incidental, but may also be the beginning of more structural change on the level of moral regimes and the moral landscape of society [35]. In this way indeed, we may conceive of future interactions between technological and moral developments in thinking about the ethical and social implications of genetic susceptibility testing.

Davison et al. emphasized the need to study the broader social and cultural context in which genetic susceptibility testing may take shape—a context shaped by earlier experiences in the field of population screening. We take this idea a step further on the basis of our co-evolutionary approach, focussing on the ways in which past and future practices of screening are mediated by an *evolving moral landscape* in our society (see Fig. 1).

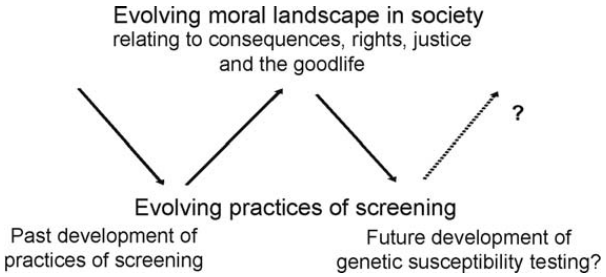

Fig. 1. Co-evolution of technology and morality. The pattern of arrows shows how past and future practices of screening are mediated by an evolving moral landscape in society.

Let us return at this point to our fictional account of a future public debate about genetic susceptibility testing for Alzheimer's disease. This account was based on the idea that future moral controversies about genetic susceptibility testing will be framed by NEST-ethics as a repertoire that is highly entrenched in the moral landscape of our society. But, how to envision the further development of this controversy? Can we imagine plausible solutions to emerge, either conforming to established moral principles, practices and beliefs, or indeed challenging and changing them? An analysis of the moral landscape can guide such imaginative efforts. Thus, in the following, we show how in past debates about population screening particular values have emerged as robust elements in the moral landscape of Dutch society. These elements then provide us with a starting point to explore future implications of genetic susceptibility testing in the form of a techno-ethical scenario. In this scenario, we show how new options for susceptibility testing might be taken up in future practices of health care, and how this process implicates a particular interaction between these new technological options and established values in the moral landscape.

3. A history of the Dutch moral landscape

3.1. Criteria of population screening

Debates about the role of (population) screening in (public) health care already have a long history. In the Netherlands, the introduction of a national programme for mammographic breast cancer screening has been especially relevant in this context. It was subject of a long debate which started in the 1970s and continued well into the 1990s, involving various scientific advisory committees, (public) health professionals, as well as the parliament.[2] The political debate also included more general discussions about the need for governmental regulation of population screening which took shape in a Population Screening Act that was finally passed in 1992. According to this law the desirability of population screening programmes has to be considered on the basis of criteria derived from the internationally accepted WHO criteria of Wilson and Jungner [37]. In policy decisions about the introduction of new screening programmes these criteria serve as a general framework, whereby evidence-based evaluation of cost-effectiveness is seen as a basic principle.

The evaluation of screening initiatives is thus largely guided by a *consequentialist* moral framework. Because screening is offered to individuals who have no complaints and have not asked for the services offered to them, the principle of no-harm is often stated as a particularly important consideration in weighing the advantages and disadvantages of screening [38]. Since many individuals have to undergo screening in order to identify a few who might benefit as a result of early diagnosis of risk or disease, the disadvantages will readily outweigh the advantages of screening. What is at issue here are not only costs in terms of money, but also costs in terms of risk, and in terms of psychological, social or ethical implications. In the debate about breast cancer screening in the Netherlands such broader issues have indeed been raised, including risks of radiation, the impact of screening on the quality of life, and undue medicalisation [36]. These broader issues are also reflected in the internationally agreed criteria for the introduction of new screening programmes, whereby, according to the officially adopted principle, the advantages of screening should clearly outweigh the disadvantages [29,39,40].

However, not only the disadvantages, but also the advantages of screening have been discussed in various terms. From a public health perspective, prevention of disease and early mortality are the principal objectives of screening and the advantages of screening should be evaluated accordingly in terms of population health gains. On the other hand, in the context of programmes of prenatal screening, prevention as a criterion of effectiveness is a more difficult and contentious issue [41,42]. In the Netherlands, for example, cost-effectiveness has been explicitly dismissed as a guiding principle in evaluations of prenatal screening. As stated in two recent reports of the Dutch Health Council on population screening, it is not effectiveness what is at issue in prenatal screening, but the possibility of reproductive choice for couples who are interested in having such a choice [38,43].

[2] The introduction of mammographic breast cancer screening in the Netherlands has been studied in our project as a historical example of interaction between technology and morality [36].

This notion of *choice* is also highly entrenched in established practices of clinical genetics and as such it has gained wider significance in evaluations of genetic screening. In 1994, for example, the Dutch Health Council [44] published a report in which the aim of genetic screening was formulated as 'enabling participants to know about the presence of a genetic condition or risk, and to take a decision on the basis of this information' (p. 124). In a further explanation of this aim it was emphasized that genetic screening programmes should be organised for the benefit of the individual participants. Societal gains, like saving health care costs, were never to be accepted as the primary aim of screening. Indeed, a growing emphasis on information and choice in the context of genetic screening has also been noted as a wider international development implying 'a shift from the aim of treating, preventing and alleviating disease – an important goal of any screening programme – to the aim of offering individual options' ([45]: p. 135).

From the foregoing we may conclude that policies of screening are guided, in the Netherlands and elsewhere, by a robust moral framework of criteria according to which screening should be cost-effective and should satisfy the additional condition that benefits clearly outweigh potential harm to those undergoing screening. But it is also clear that the priorities set in weighing desirable and undesirable consequences may be different for different kinds of programmes. Thus there is room for debate about how current (and indeed shifting) criteria should apply to particular forms of (genetic) screening.

3.2. A regime of regulation

Constituting a legal framework of regulation, the Dutch Population Screening Act can be seen as an important and characteristic element of the Dutch moral landscape, which implies a particular responsibility of the government in decisions about the introduction of new screening programmes. This responsibility is grounded in a more general constitutional obligation of the government to promote public health, through equal access to health care and measures of prevention [44]. But in relation to population screening, the responsibility of the government has taken on specific meaning in terms of *protection* of individuals against potential harm of particular screening initiatives. Especially screening of severe conditions has to be considered, according to law, with the greatest care if no options for treatment or prevention are available, although the government admitted that even without such options screening might offer particular 'psycho-social benefits' [44].

In this context the Dutch Health Council discussed, in its report about genetic screening, the implications of this legislation for current and future practices of genetic screening. Genetic screening involving serious conditions without options for treatment or prevention, obviously would require a license from the government. But the main line of argument in the report was that genetic screening, whether it requires a licence or not, is marked by sensitivities and uncertainties that need special care and consideration. Genetic screening may involve reproductive choices, information that has implications for family members, risks that are difficult to interpret and diseases that become manifest only in the distant future. There is still much uncertainty about future possibilities for genetic screening and about the ability of people to deal with these possibilities. In the history of genetic screening there is evidence of societal risks, including stigmatisation and discrimination that even today may be difficult to exclude. For all these reasons, the report emphasized the special moral responsibility of those providing genetic screening, because, in particular with genetic conditions, population screening may not only offer choices and opportunities, but also do harm to the personal well-being and social functioning of individuals. Accordingly, the report proposed that every new genetic screening programme should be subjected to an independent examination on the basis of current criteria.

What we find in the history of debates about criteria and legislation in the field of population screening in the Netherlands (and elsewhere) is an emerging *regime of regulation*, characterised by particular moral rules and a particular distribution of responsibilities in decisions about new programmes of screening. Pivotal in this regime is the aim of protection of individuals against harm. Screening should only be offered on the basis of evidence that benefits clearly outweigh harm, and some potentially harmful forms of screening are not allowed without license of the government. Screening, however, is not only offered by the government, but more and more also by other parties inside and outside the (national) health care system. Rapid scientific and technological developments involving new options for early diagnosis are going together with a notable market growth in the field of individual health checks, medical self-tests and direct-to-consumer laboratory services including genetic susceptibility tests [46–53]. It is the increasingly important role of commercial providers, offering laboratory services direct to consumers, that we took as starting point in our fictional account of a future public debate about genetic susceptibility testing for Alzheimer's disease. In our account of this debate, we have contrasted different ethical perspectives that, as the foregoing history makes clear, are deeply rooted in the moral landscape of Dutch society. From a consequentialist perspective, embodied in the current regime of regulation, protection against harm is a main concern. But, from a deontological perspective emphasizing individual autonomy, the relevance and legitimacy of this regulatory framework is seen as questionable, especially in regard to tests offered on the Internet, obtained by individuals who are seeking, and indeed paying for this service. This latter position not only reveals the traditional emphasis on information and choice in the context of genetic screening, but is also rooted, as we will see below, in a long and eventful history of moral debate. Whereas proponents of regulation may refer to rules and responsibilities that are highly entrenched in a present regime of regulation, there are indeed other robust elements in the moral landscape of (Dutch) society that may be mobilised in favour of consumer autonomy and individual empowerment.

3.3. Public health and notions of self-determination

In the 1980s protection of personal privacy and bodily integrity has been established in the Netherlands as individual constitutional rights which implied informed consent as a basic principle that subsequently has been laid down in a number of patient laws. Protection of individuals as a constitutional principle has also become manifest in public health, implying a gradual 'retreat from coercion' [54]. In the Netherlands, and internationally, the rising AIDS epidemic during the 1980s has been most revealing in this respect, when compulsory measures of control were fiercely disputed and have been generally omitted as incompatible with individual rights of privacy and self-determination [55,56]. Likewise, in policies of population screening, individuals are granted the right to refuse screening, even if there is evidence that, from a public health point of view, the benefits of screening outweigh harm. In other words, mandatory screening is rejected in respect of individual autonomy [44].

Thus, in the moral landscape of (Dutch) society, we find a tension between public health values and individual rights. This tension may take different forms. On the one hand, individual rights may be called upon as a form of protection of individuals against the dominance of public health imperatives. Indeed, in the Netherlands, in the debate about mammographic breast cancer screening, autonomy and informed choice have been put forward in the parliament as a crucial warrant against screening policies exclusively focussing on high participation rates [36]. On the other hand, notions of information and choice have become more and more recognized as an important aim in itself, especially in the context of prenatal and genetic screening. Screening then is justified in terms of individual rather than public health benefits, and the tension between individual rights and public health aims now (re)appears in another form. Even if particular options for screening are difficult to justify from a public health point of view, individuals may claim their own right to decide about these options, while denouncing as 'paternalism' official policies of restraint and protection.

In the moral landscape of (Dutch) society, notions of *self-determination* have not only been shaped in practices and policies of screening, but have also become manifest in a growing emphasis on the individual responsibility for health and disease. This notion of individual responsibility is justified by the general observation that the incidence of the most important diseases in our (future) society is strongly related to individual lifestyle [57–61]. It also implies that health and disease are not just happening to an individual, but have to be considered as the result of specific and increasingly known personal lifestyle factors [62,47,63]. As the former chairman of the Dutch Council for Public Health and Health Care recently pointed out, 'the veil of ignorance' which justifies usual notions of health, risk and solidarity, is now lifted by a growing knowledge of individual risk factors. It thus may be expected from (future) health care consumers to take opportunities for healthy behaviour and self-management of (chronic) disease more and more into account [64].

4. A techno-ethical scenario

4.1. Genetic susceptibility testing in future health care

In the context of the foregoing history of the Dutch moral landscape, we now want to explore future ethical and social implications of genetic susceptibility testing in the form of a techno-ethical scenario, focussing on the interplay of technology and morality. In constructing this scenario, we had to make assumptions with regard to uncertainties pertaining to both future *technological possibilities* and *moral developments*. We assume that knowledge of genetic susceptibilities to common diseases will rapidly increase as a result of huge investments in collaborative epidemiological research, based on large collections of human material and data in biobanks. 'High-throughput' technologies, including genomic micro-arrays, are being developed at great pace and increase the possibilities to screen individuals for large numbers of subtle genetic variations indicating particular susceptibilities to disease [65,43]. Thus, we suppose that options for screening of genetic susceptibilities to common conditions, as for example Alzheimer's disease, will increasingly become available, including commercial services offered directly to consumers through the Internet. Accordingly, we took the aforementioned tragic incident as the starting point for our scenario, and as an example of the moral controversies that may be expected, on the basis of our NEST-ethical perspective, from the introduction of genetic susceptibility testing in society. This brings us to the questions that we want to explore in our techno-ethical scenario. How to account for the further development of these controversies in the light of new and emerging possibilities for genetic susceptibility testing on the one hand, and established forms of morality on the other? Can we expect particular resolutions to emerge from these controversies, either conforming to established moral principles, practices and beliefs, or challenging and changing the moral landscape of our society?

We highlighted particular elements in the Dutch moral landscape with regard to population screening, such as the rules and principles embodied in a statutory regime of regulation and the constitutional right to self-determination. These moral rules and principles we may see as robust elements that have proved their merit and may be mobilised in any debate about the value of particular forms of screening. Mobilising general rules and principles, however, always implies a *translation* to the specificities of a particular situation. As a result, shifts may occur, at different times and places, of the importance and meanings attached to particular rules and principles of screening. This is what we have seen happening in the foregoing history of debates about screening, where information and individual choice acquired special significance as criteria of evaluation in the context of genetic screening, and as a manifestation of shifting notions of self-determination. We have also seen how in this evolving moral landscape a particular tension has been emerging between a *consequentialist* perspective emphasizing the value of protection and a *deontological* perspective emphasizing autonomy and empowerment. Thus, a

particularly important question to be addressed in our techno-ethical scenario is how these conflicting values in the moral landscape of our society might come to be weighed in future debates and practices of genetic susceptibility testing.

Obviously, we might think of plural scenarios in terms of these conflicting values. For reasons of space we have restricted ourselves to only one, as a 'proof of principle' of our techno-ethical scenario approach. We present it in the form of a *history of the future*, starting in 2012 and unfolding into a chain of events and controversies. The scenario is situated in the context of current practices and policies of health care in Dutch society. Of course, this leads to some 'couleur locale', but we believe that the main issues and controversies are relevant to other Western societies as well.

4.2. Susceptibility testing for Alzheimer's disease and beyond: expert consultation and political debate [3]

The public debate following the tragic incident in the spring of 2012 led to parliamentary questions about the responsibility of the government. The Minister of Health responded that he would seek new advice from the Health Council about how current criteria for population screening should apply to susceptibility testing. A year later, the Health Council published a report addressing two different questions. The main subject of the report was an evaluation of current possibilities for genetic susceptibility testing, focussing on Alzheimer's disease and type 2 diabetes. Both cases were evaluated in terms of the established criteria for population screening as formulated in the Health Council report on genetic screening of 1994. Accordingly, screening should relate to a serious health problem and a clearly defined target group, the available test should be reliable, and the resulting information should offer participants meaningful options for action. Moreover, screening should only be introduced when the advantages clearly outweigh the disadvantages.

Alzheimer's disease and type 2 diabetes represented two different cases in this respect. Both were serious health problems, but clearly differed in terms of available options for action. Options for treatment or prevention of Alzheimer's disease were lacking. Therefore the report doubted whether susceptibility testing would generate information 'meaningful' to participants of a screening programme. These doubts were strengthened by another important consideration: obviously tests covering only a limited number of genetic markers had virtually no predictive power in the case of a multi-factorial disease like Alzheimer. Even if tests could be based on detailed knowledge of the multiple genes involved, they would mostly point out slight deviations from a general population risk. Thus, in regard to some of the most important population screening criteria, there were no arguments, according to the Health Council, to support the introduction of susceptibility screening for Alzheimer's disease.

For type 2 diabetes, the considerations were different. In this case prevention and treatment were possible, raising the question whether there were reasons to expect public health gains from a programme of genetic susceptibility screening. In this context, the report discussed a particular scenario in which susceptibility screening was used to identify individuals at risk who then could be offered regular monitoring and personal life style education in order to prevent the development of disease. This scenario was inspired by an earlier report of the Health Council in which it had been argued that the introduction of a clinical screening programme for type 2 diabetes might be considered for particular risk groups, including individuals with a family history of the disease. But what levels of susceptibility would justify identifying someone as being 'at risk'? Moreover, who should be considered as the target group: only people above a certain age, or also children, now that type 2 diabetes is more and more developing in the younger population? Given these uncertainties, the advice concluded that there was no reason to believe that the introduction of genetic susceptibility screening might contribute to cost-effective prevention of type 2 diabetes.

The advice not only questioned the potential advantages of genetic susceptibility testing, but it also voiced concerns about its potential adverse consequences. Individuals might have difficulties to understand the risk information, resulting in unnecessary anxiety or false reassurance. As more individuals would find themselves as being at risk, they might also increasingly turn to the health care system, leading to medicalisation and rising health care costs. In the light of these concerns, the advice stressed the need to protect citizens against private initiatives offering genetic susceptibility testing on a commercial basis. In line with recent recommendations of the European Society of Human Genetics, the Council proposed to subject genetic tests to strict national licensing. The government should forbid commercial practices of genetic susceptibility testing that did not meet generally accepted standards for population screening. If independent and evidence-based evaluation did not warrant the provision of susceptibility screening in the public health care system, why indeed allow other parties the right to provide such services, with potential harmful consequences for individual users and society at large?

In the ensuing political debate, the two messages of the report were quite differently received. The Minister of Health readily accepted the conclusion that there is no place for genetic susceptibility screening in the context of public health policy. However, she rejected the proposal to completely subject the provision and use of susceptibility tests to government regulation. Neither the current Population Screening Act, nor European rules would provide for such a comprehensive form of regulation. More importantly, for the government the individual responsibility and the right to self-determination of citizens for their personal health were tantamount. The Minister agreed that commercial tests had to meet standards of quality, and individuals applying for such a test should be well informed about their proper use and limitations. But in the end, the individual should decide. In the Parliament this position met with wide-spread support, especially from the more liberal oriented parties who praised the Christian-Democratic Minister for not giving in to patronising. In their view, the

[3] Literature used as an additional source of information in this section: [66–75].

Health Council was mistaken in considering the commercial provision of genetic tests in terms of population screening. Whereas population screening implied an unsolicited and systematic invitation to participate, and thus had to be justified by a collective process of decision-making, it was the individual who applies for a test in the case of commercial services. Accordingly, it was not the government, but the individual who should weigh, in the light of personal values, convictions and experiences, the advantages and disadvantages of screening.

4.3. Diabetes: an emerging regime of individualised prevention [4]

The debate about genetic susceptibility screening took place in the context of a public health policy based on two important principles. First of all, citizens had to be protected from harm resulting from activities of others. More and more, however, the promotion of healthy behaviour became another cornerstone of public health policy, emphasizing individual responsibility for personal health. Thus, after the turn of the century, education about lifestyle risks and measures stimulating healthy behaviour were gaining importance in order to stimulate prevention. As time went by, however, disillusionment grew. Alarmed by the incessant and 'epidemic' increase of obesity and type 2 diabetes, the government decided, in 2014, for a more targeted approach. Based on earlier recommendations of the Dutch Health Council to consider systematic clinical screening for type 2 diabetes, a programme was initiated aiming at the identification of individuals at risk for developing type 2 diabetes by general practitioners and the youth health services. Beside obesity as a most obvious risk factor, the programme also focussed on family history. Those meeting the criteria were offered personal lifestyle advice and regular monitoring.

The programme was introduced as an extended pilot study in cooperation with one of the larger Dutch health insurance companies, which would offer reimbursement for counselling and support of individuals found at risk. General practitioners were invited to include in the pilot patients insured by the company. In addition, a number of youth health services participated on the basis of special funding from the public health budget. In the medical world, however, the programme soon caused fierce debate. A considerable number of general practitioners was reluctant to participate and some of them took the effort to explain why in articles and comments published in some of the main Dutch medical periodicals. Without denying that general practitioners do have a preventive task, they resisted the basic idea of the programme that healthy individuals should be counselled about lifestyle rules and invited to have themselves monitored, only because of a family history of obesity and diabetes. The programme, according to some particularly critical commentators, raised the spectre of a preventive control state.

Physicians who did participate in the programme were struggling with comparable questions on a more concrete level. When facing patients showing signs of obesity or early diabetes, they would not only have to invite them for counselling and regular monitoring, but also to query them about their family histories. What to do then, when this query indicates a family history of obesity or diabetes? Other members of the family were to be invited for a consultation. But, to what extent and how emphatically should the doctor in this preventive role take responsibility for the individual patient's family? Related, but more specific questions were faced by physicians participating from the youth health services. Is it justified, to trouble healthy children coming from families with a clear history of obesity and diabetes with a programme of counselling and monitoring? At which point did serving public health turn into violating the private life? In response to these questions, guidelines were developed, assigning to physicians the responsibility to approach close relatives of individuals at risk, but also stipulating that children should only be introduced to the programme by their own parents.

In 2017, two Dutch genome researchers published a striking proposal in the *Dutch Journal of Medicine*. Genetic susceptibility testing, based on micro-arrays including a large number of genetic markers, was becoming a real possibility and thus, the authors argued, might be used as a tool in targeting individuals at risk for developing type 2 diabetes. This would entail a more cost-effective approach than targeting all individuals sharing a particular family history. It would also resolve some of the more delicate questions about how to justify the inclusion of healthy relatives and children in such a programme. And, even more important, in stimulating individuals to adopt a healthy lifestyle and to commit themselves to regular monitoring, an individualised genetic risk profile might be more effective than the more general risk information based on family history.

The proposal provoked an immediate response from some well-known clinical geneticists. They sympathised with the idea of personal genetic information as a valuable resource in individual decision-making, but also voiced serious reservations. Whereas the personalized character of risk information was indeed a source of empowerment in matters of health and lifestyle, its genetic nature, on the other hand, might just as well cause fatalism. There was also the danger of misunderstanding a 'good' genetic profile as a licence to continue an unhealthy lifestyle. Clinical geneticists knew all too well how difficult it is for individuals to deal with complex genetic information. The introduction of genetic susceptibility screening in a programme of prevention thus implied, as the authors emphasized, a tremendous challenge in terms of counselling. Would the costs of such an effort really justify the benefits? These considerations obviously got the ear of the health insurer involved in the programme. It had no interest in an initiative involving extra costs for testing and counselling while limiting the number of potential beneficiaries of the programme to a more restricted risk population.

[4] Literature used as an additional source of information in this section: [76–95].

4.4. Genetic profiling revisited [5]

The pilot programme not only aroused professional interest and debate, but also had other implications as well. In an attempt to secure the client's favour, other health insurance companies became interested in supporting the programme. This interest reflected a growing awareness among health care consumers of the importance of lifestyle and family history as risk factors in developing diabetes. Indeed, the rise of public awareness was a result of sustained efforts by the government and patient organisations to promote healthy behaviour. It was further strengthened by the publicity that accompanied the pilot programme. Moreover, as a result of considerable investments in genomics research, an increasing number of firms started to offer programmes of genetic susceptibility testing on the Internet, including risk profiling for type 2 diabetes. Some firms also offered a follow-up for clients who showed an enhanced risk for some common and chronic diseases, consisting of regular health checks on the basis of molecular biomarkers that might indicate minute and early signs of disease. Knowledge of such biomarkers rapidly increased thanks to progress in genomics, proteomics, metabolomics and bio-nanotechnology.

As a result of these developments, individuals were more and more addressed in terms of looming health risks that may be averted by taking proper action, based on information about personal risk profiles. In this context, there was a growing interest from individual health consumers for commercially provided genetic tests, especially from individuals who wanted to know about their personal susceptibility for diabetes. For some, it was just a matter of curiosity or reassurance about one's personal health. For others, such tests were attractive as a source of information which they perceived as highly personal and not to be shared with a doctor without need. But, a most significant group interested in these tests, were those who wanted to know more of their own risk status because of diabetes running in the family.

Although tests were available at a reasonable price, commercial follow-up services were still experimental and expensive. Many of those who learned about their risk for diabetes on the basis of a commercial genetic test, thus preferred to go to their own doctor for further counselling and monitoring. If there were other indications for being at risk, like a family history, individuals could be included in the preventive diabetes programme, which by now (from 2020) had acquired a national status and was covered by all health insurers. But how to treat individuals who turned to the health care system with no other evidence than the results of a commercial genetic test? In 2022, a twenty-eight year young woman, who had consulted her doctor after having learnt about her risk for diabetes from a commercial genetic test, filed a complaint against her health insurer for denying her reimbursement of subsequent counselling and monitoring. In its decision, the company had noted that, according to the national guidelines, the only grounds for inclusion in a programme of prevention were physical risk factors like obesity, or one's family history.

This incident reopened earlier debates about the potential role and significance of genetic susceptibility tests as a tool in a programme of prevention, and it was decided to ask a special expert committee for advice on this question. In its report the committee observed that genetic susceptibility tests were becoming increasingly informative and now had become widely available and accessible to health consumers. Although information from these tests, in most cases, only indicated slight individual deviations from a general population risk, it was in this respect not different from information based on family history. The committee, then, saw no reasons to rate family history higher than a genetic susceptibility test. On the contrary, it welcomed the fact that such tests were perceived by individuals as an incentive to seek support from available programmes of prevention.

However, as the committee pointed out, the question should not only be considered in terms of information and empowerment, but also in terms of justice. If information from genetic tests was accepted as a legitimate ground for inclusion in a preventive programme, the availability of these tests should no longer depend on people's willingness or ability to pay. Therefore, the committee proposed to reimburse genetic tests as part of the programme. And this proposal was presented as crucial for other reasons as well. The committee voiced great concern about the lack of proper information and counselling in practices of commercial susceptibility testing. A most serious worry in this respect were incidental reports about parents having their children tested, apparently without considering the implications. Only by including genetic susceptibility tests in a proper programme of prevention, it would become possible to offer individuals the information and counselling they need, and to warrant the necessary protection of children in decision-making about these tests.

The committee's report was a new intervention in a protracted debate about the organisation of the preventive diabetes programme and the role of genetic susceptibility testing in particular. As such it did not remain without response. A most critical reaction appeared in the *Dutch Journal of Medicine* from a group of epidemiologists. They strongly criticized the committee for being dominated by clinicians and geneticists, thus neglecting the epidemiological point of view. Especially worrisome, in their view, was the increasing individualisation of diabetes prevention, emphasizing individual risk factors at the cost of some well-established epidemiological truths. It was well-known that the emerging diabetes epidemic had everything to do with obesity, lack of physical activity and a diet dominated by fat and sugar, risk factors that were clearly related to wider social and economic determinants of health in populations. Thus, the authors dismissed current policies of prevention for its pre-occupation with identifying high risk individuals, and for ignoring, through its focus on individual lifestyle choices, crucial social, economic and cultural factors. Most sceptical, in this respect, were the authors about the identification of genetic susceptibilities, wrongly stigmatising individuals as being at risk and subjecting them to a costly 'regime' of medical surveillance.

[5] Literature used as an additional source of information in this section: [96–104].

These arguments, however, found little response among those involved in current policies and practices of prevention. Of course, obesity was an all-important risk factor, as indeed nobody would deny. But we should not be lured into a debate, based on a false contrast between general, often fruitless policies of prevention, and badly needed attempts at a more targeted approach. So, general measures of prevention had to be complemented with practices addressing individuals in much more direct ways. Moreover, even in common diseases like type 2 diabetes, genetic variations were always involved in some way. It was in this context that genetic susceptibility tests, according to its proponents, should be welcomed as a tool potentially empowering individuals to a more healthy lifestyle, whatever the limitations of the information provided by these tests.

5. Conclusion

Our scenario approach is based on the idea that future ethical and social implications of new technologies, like genetic susceptibility testing, have to be understood by taking into account the ongoing interaction between technological and moral developments. We have shown how this interaction can be systematically explored in the form of a techno-ethical scenario. We constructed a complex future of changing technology, disease concepts, health related practices, social relations, and indeed changing values as well. Our aim was to create a plausible story, showing how values may be mobilised by different actors in favour or against new options for genetic susceptibility testing and how in this process morality and technology interfere. Although our approach shares the aim of a structured exploration of the future with other scenario exercises focussing on genomics and society, it is particularly distinct for the way in which it explores the interaction between genomic technologies and societal values [105].

What are the implications and indeed applications of our approach in the context of societal debates about future social and ethical implications of new and emerging technologies? Here it is relevant to distinguish between NEST-ethics on the one hand and techno-ethical scenario construction on the other. NEST-ethics can be used as a mapping tool which allows us to explore moral controversies in a systematic way. This approach can be especially helpful for policy-makers and other stakeholders in timely *recognizing* controversies, in *understanding* these controversies in terms of typical patterns of argumentation, and in *enriching* these controversies with arguments that in policy debates may become (too) easily marginalised. The construction of techno-ethical scenarios allows us to explore potential controversies in a pro-active way by imagining how NEST-ethical arguments may interact with processes of socio-technical change. This approach may again help policy-makers and other stakeholders to *recognize* future controversies in a timely way, to *understand* these controversies as being shaped by a particular societal dynamics, and to *manage* these potential controversies in a sensible way by involving various parties in debates in which both the plausibility and desirability of particular scenarios can be scrutinised. In this way, techno-ethical scenarios can help us to conceive of a future technology in a rich, socially and morally embedded form. By opening a reflexive distance towards present as well as potential future morals, techno-ethical scenarios also help us to enrich and multiply perspectives from which to judge current and future developments.

In the foregoing we presented one particular scenario as a 'proof of principle' of our approach. What can we learn from this techno-ethical scenario about the potential future interaction between technology and morality in the field of genetic susceptibility testing? In our scenario we have described ongoing interactions between *genetic susceptibility tests* as a new and emerging technology and an *evolving moral landscape* characterised by a tension between a consequentialist perspective emphasizing the value of protection and a deontological perspective emphasizing autonomy and empowerment. An important question we wanted to address in our scenario was how these conflicting values will come to be weighed in future debates and practices of genetic susceptibility testing. What we have seen in our scenario is that the value of individual *self-determination* was effectively mobilised to resist pleas to restrict the introduction and use of genetic susceptibility testing. Vice versa, technological developments made it possible to provide tests, ever more efficiently and cheaply, directly to individual health consumers. In this way, technological developments shaped conditions in which the societal introduction and use of genetic susceptibility tests more and more became a matter of private decisions, thus *reinforcing* claims to individual self-determination as a predominant value in this context.

The value of self-determination also became embodied in our scenario through an emerging regime of individual prevention, focussing on individual lifestyle decisions. This regime too, created conditions contributing to the broader acceptance of susceptibility testing. But again, the growing technological possibilities to identify individual risk factors further *strengthened* this regime and its embodied value of individual self-determination. Indeed, in our scenario, the effectiveness of genetic susceptibility tests came to be evaluated, not so much in terms of public health values, but in terms of empowerment, that is, its potential to stimulate awareness about individual lifestyle choices. Thus, in the interaction between emerging options for genetic susceptibility testing and an evolving moral landscape in (Dutch) society, individual self-determination appeared in our scenario as a prevailing value.

In what sense can we speak of *moral change* as a result of the interaction between technological and moral developments? The values that become manifest in our history of the future have a long history and we cannot say that the interpretation of these values has been fundamentally challenged as a result of the introduction of genetic susceptibility testing. However, values may gain force and influence in our society as a result of new ways and options to put them into practice. By opening up new practical avenues, technology can make some values more realisable and thus help to strengthen them. This is indeed what happened in our story to the value of self-determination as a result of the introduction of new options for genetic susceptibility testing. We might even compare this mechanism to that of a genome. Like genes, the 'expression' of deeply

rooted values in our society is influenced by other values – as protection or justice in the case of self-determination – but also by 'environmental' conditions, as embodied for example in technology [106].

There is another point to make about the way in which technology and morality interact in our story. As we already pointed out, in creating a techno-ethical scenario we had to deal with two uncertainties at the same time. One critical uncertainty pertained to the future prospects of a new and emerging technology: will promises and expectations about useful and meaningful options for susceptibility screening indeed come true? The answer to this question, however, will not only depend on future scientific and technological developments, but also on the moral framework in terms of which these developments are going to be evaluated. From a consequentialist cost-benefit perspective which underlies current regulatory regimes of population screening, expectations about genetic susceptibility testing have to be evaluated in terms of well-supported evidence for significant public health gains. From a deontological perspective, on the other hand, these expectations will first of all be evaluated in terms of a personal right to genetic information that, whatever its limitations, may empower individuals in taking decisions concerning their own health and life. In other words, if individual self-determination indeed appears as a prevailing value in the future, strengthened by the emergence of genetic susceptibility testing, promising expectations about this technology may come true, as our scenario shows, even without the strong evidence it would need from an evidence-based public health perspective.

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