

**SCIENCE COMMUNICATION AND SCIENCE POLICY:
ESTONIAN MEDIA DISCOURSE ON THE GENETIC
DATABASE PROJECT**

Tiiu Hallap

University of Tartu

Abstract. The paper is a reflection on the Estonian media debates on the nation-wide genetic database project (the Estonian Human Genome Project). Its main concern is to consider the position of a non-specialist but reflective reader with respect to the scientific information offered in the media. It is asked whether rhetoric or argument has played a more prominent role in the discussions. Some major topics and attitudes are identified. The observations on the media are put into the context of some well-known theses concerning science communication. The paper also reflects more generally on the topics of informing about science and public participation, considering briefly some recent practical and theoretical developments in science policy in Europe and the US.

Keywords: genetic databases, science communication, science policy, genetic homogeneity, pharmacogenetics, genetic determinism

1. Introduction

The Estonian Human Genome Project was launched in 1999, with the objective of establishing a nation-wide database of health and genetic data. It will contain phenotype and genotype data on the entire adult population of Estonia (around 1 million people). The database is expected to contribute to the improvement of the methods of diagnosis and treatment in medicine, the chief purpose being the exploration of the genetic causes of common diseases. At the immediately practical level, it is hoped that the database will enable to assess the specific disease risks of individual persons. The major clients of the database, however, would not be individuals, but research institutions and companies in the fields of bioinformatics, biotechnology, and pharmaceuticals. By September 2003 samples had been collected from about 4,000 gene donors, and this number may rise to 10,000 by the end of 2003. Analogous or somewhat different projects, with varying designs and property arrangements, are under way in several other countries,

including Iceland, Britain, Sweden, Canada and Tonga. Still other countries (e.g. Germany) are considering the possibility of creating population databases.

From the very beginning, Estonian and foreign media have devoted quite a lot of attention to the databank project. In the last 3 years, over 230 articles and opinions on this topic have been published in the Estonian media. There have been some periods of time where the interest of media has been especially high, with articles, interviews and opinions on the gene bank project appearing almost every day. In 2003, however, the interest of the domestic press seems to have significantly waned.

As to the exact extent of domestic and foreign media interest in the Estonian database project, there are somewhat conflicting assessments. In July 2003, the Head of Information of the Estonian Genome Project was of the opinion (Koik 2003) that “since 1999, Estonian, as well as foreign media have expressed considerable interest in the Estonian Genome Project. ... Over the last three years, foreign media have published more than fifty major articles on the Estonian Genome Project. ...Estonians have been treated to lively debate.” However, Pálsson and Harðardóttir (2002:273) say that

A detailed comparison of the biogenetics projects of Britain, Estonia, Iceland and Sweden, the ways in which they have been discussed domestically and internationally.... [reveals] a striking contrast. While the Icelandic Biogenetic Project has been the center of controversy and widespread discussion, in Britain, Estonia, and Sweden there has been virtually no public dialogue on similar projects. Moreover, the international press and the transnational scientific and bioethical communities have been heavily focused on the Icelandic Biogenetic Project, whereas the British, Estonian, and Swedish efforts have received scant attention.¹

In quantitative terms, over 200 media items of the domestic press may seem a lot, especially for a small country like Estonia. However, there is reason to have a look at this media material from the viewpoint of its actual informative value. This is what the present paper attempts to do.

2. Methodological note

There exist a wide variety of techniques and approaches for studying media discourse. One important class of these methods is referred to as “discourse analysis”. Such analysis may be both qualitative and quantitative, and is actually not a separate discipline, but rather an interdisciplinary field which embraces very different approaches. These range from analyses aiming at impartial, objective description to approaches which take an active, politicised attitude. An interesting example of how these techniques can be applied specifically to media discourse on

¹ True, this latter statement obviously concerns a significantly earlier phase of the Estonian genome project: Pálsson’s and Harðardóttir’s article was accepted for publication in August 2001, so it cannot reflect later developments. However, on the basis of actual media material it seems wrong to say that in the other half of 2001 the real debates in the Estonian press were just beginning, or that these debates became more substantial than they had been before.

science is Erkki Kauhanen's survey of science and pseudoscience discourse in major Finnish newspapers (Kauhanen 1997). Celeste Condit's study (Condit 1999) is a thorough survey of some dominant trends in the US media genetics discourse from the 1910s to the 1990s. In some countries (e.g. in the UK), there is a long-standing research tradition called "the public understanding of science" which has close connections with discourse analysis, but which also uses models and methods of its own. In addition, the scientific discourse may be studied from the sociological perspective (Gilbert and Mulkay 1984), or from a viewpoint which focuses almost entirely on linguistic issues, trying to synthesise the insights of rhetoric, functional linguistics and critical theory (Martin and Veel 1998). There are still other possibilities: specifically, concerning the discourse on genetic databases, Gisli Pálsson with co-authors (Pálsson and Harðardóttir 2002; Pálsson and Rabinow 2001) and Hilary Rose (2001) have studied the Icelandic debates from an anthropological viewpoint.

The present study has not directly applied any special techniques of discourse analysis, or any particular theoretical framework. The initial research task was to identify important types of argumentation in the Estonian database debates, maybe to find hints of different philosophies or ideologies underlying different kinds of arguments. This task proved more or less impossible because there was too little rational argument to be found in the discourse – there was simply not enough material to be subjected to analysis. To some extent, this general impression of irrationality was a surprise and seemed worth recording and discussing. Also, it raised more general doubts about whether media debates over complex scientific issues have any real informative value at all; it prompted to ask whether there are any alternatives to media discussions, and even whether or why informing is possible or necessary at all. What follows, then, is to a large extent a practically oriented reflection. In part, I have attempted to take the position of an imaginary – non-specialist, but rational – reader who wishes to reach an informed and considered judgement on the database project, and to find out what his or her situation roughly is with respect to the scientific information offered in the media. On the other hand, I shall relate my observations to a broader philosophical context concerning some recent developments in philosophy of science and science policy.

The study is based on print media material only. The articles, interviews, opinions and news items considered cover the period of time from 1999 (beginning with the first news about the gene databank project) to June 2002. The overwhelming part of the items comes from two greatest daily newspapers, *Eesti Päevaleht* and *Postimees* with its weekly supplement *Arter*. The sample was created electronically, using a set of keywords wide enough to allow one to think that all relevant media material which in whatever way referred to the database project had been taken into account. This material was read and analysed several times.²

² For the details of the sample, see Tammpuu (2003) in this issue of *Trames*. The names of the newspapers will be abbreviated as follows: PM – *Postimees*, EPL – *Eesti Päevaleht*, EE – *Eesti Ekspress*, ÄP – *Äripäev*.

3. Science communication

Before proceeding to the discourse, I shall mention three theses which one often encounters, in various forms, in public surveys and science communication studies:

- The public gets most of the information about science from the media.
- The public is ignorant about science.
- The media are unable to communicate science effectively.

On the first thesis, there is consensus.³ The other two are more controversial. When one talks about ignorance, what is usually meant is the knowledge of scientific facts or methods. Empirical research shows unambiguously that the knowledge of facts is very poor: in 1989, 31% of the Britons knew which one is smaller, the atom or the electron (Durant *et al.* 1989); in 1996, only 36% of Europeans thought there are genes in ordinary tomatoes (Bauer and Bonfadelli 2002). As to the knowledge of methods, only about 9% of the Europeans have some idea of the essential elements of scientific procedures, including such notions as experiment, control group, probability, testing of hypotheses, *etc* (Durant *et al.* 1991). The point about ignorance is usually not explicitly made in the form saying that the laypeople are actually less reflective or rational than the experts. Some research results indicate that the point about low rationality might not necessarily apply. For example, Macer's study on the Japanese biotechnology debates (Macer 1992) demonstrated a similar level of sophistication and deepness of answers and reasoning for the public, teachers of biology, and academics. And the SCST report (Select Committee on Science and Technology 2000: paragraph 2.56), referring to the studies found in (Irvin and Wynne 1996), is of the opinion that "Many ordinary people are well capable not only of reasonable judgment, but even of sophisticated reasoning, provided they are adequately informed."

As to the other thesis – the media are unable to communicate science effectively – this seems to be something that most scientists firmly believe. A recent survey by Wellcome Trust (MORI and Wellcome Trust 2000) explored the attitudes of over 1600 British scientists:

- Only 6% of the scientists trust the journalists writing for national newspapers with respect to factual correctness;
- 11% of the scientists believe that the journalists are able to discuss adequately the social and ethical implications of scientific projects;

The following two results are also of interest:

- 75% of the scientists believe that the greatest barrier in understanding science is the ignorance or lack of interest by the public;

³ See, e.g. the SCST report (Select Committee on Science and Technology 2000: paragraph 7.1. and the references therein).

- 20% believe that the scientists themselves are incapable of communicating effectively with the media and the public.⁴

The idea of the incapability of the media has different versions. One should distinguish at least between the following three forms (Kauhanen 1997):

- Science is presented in a way which is factually inaccurate;
- Science is presented in a way which is not transparent;
- Science media are in the last stage of decline.

The first version was thoroughly explored by the ‘accuracy research’ tradition in the 1970s and 1980s. The main point to be noted here is the fact that empirical studies do not confirm the idea that science stories are significantly less accurate than other kind of stories. The second version stresses the point that the media tend to present only the end results of the scientific process, without giving any idea of the arguments and procedures leading to these results. Unfortunately, the facts and results cannot be really understood when separated from their context. The third, decline version belongs to John Burnham. It is based on American material and claims that science reporting in the US media has gone through four phases: diffusion, popularisation, dilution, and trivialisation. These phases have occurred in the same order at least in psychology, medicine, and natural science. The key words of the last stages are: sensationalism, irrational appeals to authority, isolated fact format, and ‘ritual’ writing (instead of the content and meaning of research, meetings and conferences of scientists are now the main news events).

4. Participants

Proceeding now to the Estonian media discourse on the genetic database project, I will note two points as regards the participants of the debates. First, leaving aside items produced by professional journalists, it is clear that the overwhelming majority of pronouncements belong to biomedical professionals. Non-specialists have made almost no comment on the database issue. Those who express their opinion or are interviewed by journalists are senior academics, mostly at professor level. The second remark concerns science journalists. There exists an opinion, according to which the quality of a science story is greatly influenced by the fact whether the author is a journalist specialized on science reporting or not. The British SCST report, for instance, is clearly of this opinion.

⁴ Apart from empirical surveys, journalists often seem to think that the scientists’ attitude towards the media is excessively negative. Kauhanen (1997:74) asserts that “Already long time ago it became popular among scientists to complain about poor quality of science writing and it has been a common wisdom in science community ever since”, and Horace Judson (2001:769) states that “Scientists talk to the media, then the media talk to the public – and then the scientists complain that the media get it wrong and that politicians and public are misinformed. What the media do is mediate. Public misinformation is largely and in origin the fault of scientists themselves.”

When, for example, discussing the British media crisis concerning GM food (in 1999), the decisive factor in the creation of media noise is seen to have been the weak participation by professional science journalists. Among other things, the report declares that science journalism in the UK is now flourishing, and supports this assessment with the fact that the number of science journalists in the UK has increased in the last years (in 2000, there were 10 science journalists at 3 major British national newspapers). Compared to this, the situation in Estonia appears to be different. Most of the media production considered in the present study comes from three major newspapers, which have altogether only one professional science journalist. It also seems that the production of this one journalist is not of significantly higher quality than that of ordinary reporters. It may well be that at present there are no competent science journalists in Estonia. Perhaps this fact is in part responsible for some weaknesses of the database debates. However, it is not certain that this is the decisive factor.

5. Problems with interpretation of statements

One of the difficulties which a reflective reader of the Estonian database discourse will face is the problem of what scientifically-looking statements really mean. One often finds in the discourse quantitative claims like these:

Only 20% of the nation's health is determined by genetic factors. (28.10.99 EPL)

Presently, we can predict a disease with 30% probability. (17.09.2001 EPL)

Such claims are meant as pros or cons for the project. In principle, they might indeed serve as such and greatly influence the attitude of an ordinary citizen. For example, if the first thesis were well substantiated, one might reasonably think that genetic research – and the database project – is not of prime importance, as compared to other health care projects or research programs. However, the actual meaning or content of such declarations remains usually unclear as they are presented without adequate context. As to the first claim, for example, the 20% is taken from a UN report. It is mentioned several times in the discourse: the opponents present it as an argument against the database project, and the supporters say that these 20% are “old data”. Here, it is likely that the 20% is not data in any normal sense, but a rather speculative assessment, based on some specific body of data, which may or may not cover all countries of the world, or only the developed countries, or only the UN member states, or something else. When discussing the database project, it would be interesting and relevant to know at least something about the exact scope, empirical basis and theoretical assumptions of the UN report. But these things are never discussed. The same kind of remark applies to the second claim. At first glance, an unsophisticated reader may even take it to mean that out of every 10 visits to the doctor, in 7 cases the doctor's diagnosis is mistaken. In all probability, this is not what is meant. Rather, the statement may have to do with genetic methods of diagnosis: it may mean, for

example, that out of every 10 diagnoses made on genetic basis, 3 are later confirmed by other methods. Or it may mean something else. When one tries to clarify this, looking for the context, things become even more puzzling.

Aren't the diseases partially caused by chance, fluctuations, "illness of molecules"? – Certainly. If we can predict a disease with 50% probability, it's fine. At present, we can do this with 30% probability.

"Illness of molecules" and molecular fluctuations have hardly anything to do with genetic diagnostics; in spite of the apparent scientificity, it all seems quite nonsensical.

Confining myself to these two examples, I think that a reflective reader, when confronting such declarations, will waste some time on interpretation and assessment efforts, but will end up frustrated and will probably discard all such claims from his or her considerations. It may of course be that such interpretation problems derive wholly from the incompetence of the journalists. However, at least some biomedical professionals seem to regard such methods of opaque informing as appropriate. To bring an example: at a workshop where the draft of this paper was discussed, a respected physician (and member of the Ethics Committee of the Estonian Human Genome Foundation) reacted to the aforementioned remarks with the following: "Well, 20% or 30%, what's the problem? Science says so."

6. Genetic homogeneity

As to the scientific rationale of the Estonian database project, the discussions have especially often touched upon two issues: genetic homogeneity and etiology (causation) of disease. First, about homogeneity.

When discussing the project, it has been declared more than once that the Estonian population is somehow especially suitable for creating a population database. More precisely, it has been said that this is due to the genetic homogeneity of the population. In connection with this topic, it has also been discussed whether the aim of finding genes "for" diseases (or susceptibility genes) is better realised by a research project which deals with an entire population, or by a project which focuses on small samples from risk groups. I shall next present 9 statements concerning these issues which are not illustrative examples but appear to represent the whole body of information available on this issue in the media (for the period of time under consideration). Almost all statements are made by professors:

1. *Iceland and Estonia are genetically homogeneous societies.* (17.09.2001 EPL)

2. *The population of Iceland is genetically and culturally homogeneous.* (07.09.2001 ÄP)

3. *DeCode will never discover anything valuable, since Stefansson's assumption about the genetic homogeneity of Icelanders is false. Actually, Iceland is one of the most heterogeneous countries of Europe.* (05.04.2001 EE)

4. *The genetic pool of Estonians is relatively uniform, we do not differ from the rest of Western Europe with respect to the frequencies of any disease. ...The internal genetic homogeneity of Iceland is a myth.* (04.11.99 EE)
5. *An essential objection to the efficiency of the Gene Bank is the extreme heterogeneity of the Estonian nation. ... In Estonia, one often does not know even one's father, not to speak about grandfathers and their fathers. ... Without adequate genealogy, the Gene Bank will not work, because it is based on accidental data.* (15.08.00 EPL)
6. *Among genetically mixed nations, persons are genetically so different that the genes causing diseases are overshadowed by other genes. Stefansson said that among Icelanders great genetic variations directly cause diseases, not minor things, such as different eye colour.* (05.04.2001 EE)
7. *In order to precisely identify genes causing diseases it is insufficient to analyse a couple of hundreds of patients – one needs the whole body of data from one national community... Estonians are an ideal opportunity for conducting such research.* (10.06.00 Arter)
8. *In order to identify the risks (susceptibilities), one does not need an expensive gene bank; it is enough to study the genes of a limited number of people.* (08.11.99 EPL)
9. *In fact, there are two methods for discovering new genes. Iceland wants to use genealogies. ... We plan to use a more modern and more precise method which amounts to using many people in the research. We need 1000-2000 patients with the same diagnosis. Then the genotypes of patients can be compared and the gene which causes the disease might be found.* (04.11.99 EE)

Obviously, this body of information contains some ambiguity, a great diversity of opinion, and no real argument. As to the concept of homogeneity, for example, one talks simply about “mixed nations”, but also in terms of the frequencies of diseases. The first notion is perhaps intuitively clear, whereas the second is not. The relationship between these two ideas cannot be considered evident. (The ‘correct’ definition of homogeneity/heterogeneity is, as it seems, to be given in terms of ‘linkage disequilibrium’: although this is not quite certain either. See below.) As for the role of genealogies, we have an opinion which sees genealogy as decisive, and another which holds that the “method of many people” is more exact than the genealogical method. No attempt is made to explain in more detail the advantages or drawbacks of competing methods, or of small and large samples. We also have a number of views with respect to the issue whether Estonia and Iceland are similar or different and whether each of them is homogenous or not.

To make a digression here, Hilary Rose’s study on Icelandic debates gives the impression that, in Iceland’s case, the issue of homogeneity is (or at least was) no more clear – but as important – as in the Estonian case. Rose refers to “what is endlessly spoken of as the genetic homogeneity of the population” (Rose 2001: 13), and presents some criticisms against deCode’s claim of isolation and homogeneity. After studying what Rose says one ends up with some more items for the list presented above: to everything what was said about homogeneity in Iceland and Estonia in the Estonian discourse, two statements by the distinguished

geneticist Luca Cavalli Sforza can be added: 1) Iceland shares the European genetic profile and is much less different from this general pattern than Sardinia; 2) current research may show that Icelandic population is not as homogenous as might be expected.⁵

In the course of writing this paper, I made an attempt to clarify at least a bit the homogeneity issue and posed the following question to the Estonian Human Genome Foundation, asking for an ‘official statement’ as to which of the following two opinions (heard from two scientists engaged in the database project at an informal workshop) is true: a) homogeneity was initially regarded as an essential condition, but recent research has shown that heterogeneity does not really matter; b) it was known from the beginning that homogeneity does not matter (because otherwise it would be impossible to apply the data to heterogeneous populations). As an answer to this question, I received the statement “let us declare unambiguously that heterogeneity is clearly preferable”. However, this statement was soon withdrawn as expressing personal opinion and I was asked to wait for the official answer. This I received some days later and it went like this (Metspalu 2003):

On the basis of the available research data, the Estonian population may be classified as heterogeneous. Linkage disequilibrium is similar in the Estonian, German, and English population. There is also some research on the Y-chromosome and on the mitochondrial DNA which confirms this view. This accords well with the aims of the Estonian Genome Foundation because using a dense network of SNPs, we will be able to cover, according to the estimates, the whole genome or its coding part (the exons), so that for 85% of people we shall be able to characterize at least 85% of the genomic fragments (the so-called haplotype blocs). This will enable to conduct research which is planned. The characterization of the genome and of all individuals will take place continually, according to the available possibilities and to the new information acquired.

The drawback of a homogenous population would be that the size of the so-called haplotype bloc would be much greater than in case of a heterogeneous population. In this latter case, more time and effort would be required in order to find from this bloc (where there may be many genes) a gene causing a disease (or something like that). Although initially one would need less markers. Also, homogenous populations are small and do not contain many important gene variations (alleles).

⁵ Pálsson and Harðardóttir (2002:275–6) also comment on the issue of homogeneity: “The gene pool is fairly homogenous.... Given these characteristics and the small size of the population, the Icelandic gene pool may have advantages for the genetic and medical research.” However, they qualify this with a footnote: “Icelanders are no genetic Robinson Crusoes. Throughout its written history, Iceland has regularly been visited by slaves, pirates, fishermen, and travelers. Recent research in ‘biological anthropology’, based on DNA analysis and demographic studies, indicates that while Icelanders are more homogenous than most other European populations they nevertheless contain a surprising amount of genetic diversity for a small island population.” For interesting details about Iceland’s settlement history and deCode’s ‘updated’ version of this history see Rose (2001:13–14).

Informative as this reply is, it did not quite answer the question – which aimed to find out whether talk of homogeneity was just a rhetorical device from the very beginning, or whether some elements in the scientific rationale of the project have significantly changed in a couple of years (which may mean that this rationale is not very reliable or secure). Although it would be interesting to know, it is not the main concern here. I merely want to point out that the situation of a non-specialist though moderately educated reader when assessing such aspects of the database project as the homogeneity issue, on the basis of media news and articles, seems to be hopeless: the more so, when one takes into account the fact that an ordinary reader cannot spend a whole year, reading and comparing over 200 media items and other literature – as a discourse analyst or a philosophy professional may do.

7. Genetic determinism

Quite often, issues have been raised within the context of the Estonian debates which have to do with the causes of disease. One may refer to this kind of issues as ‘genetic determinism’. In the present context, genetic determinism means the idea that the role of genes in the emergence of diseases is causally decisive. Not always, however, is discussion limited to diseases: there is also some talk on the genetic determination of any human traits. The term itself – genetic determinism – figures only a couple of times; no article is devoted specifically to this topic. The headlines and subheadings occasionally refer to determinism, sometimes in a dramatic tone: “Genes and our fate”, “Everything is in the genes”. Several times, the issue of determinism is raised in interviews with the initiators of the project: “What is the exact relation between diseases and genes? Do genes determine all diseases?”

I shall next bring a set of statements, which all have to do with ideas concerning the causation of diseases. Those statements have been chosen which are more clear, leaving aside those which are too hard to interpret:

It may be said that all diseases are genetic. (13.03.00 PM)

Most of the diseases are genetic, including those which are not heritable. (13.02.01 PM)

The direct influence of genes is confined to the particular cell where the gene is located. Only distant, indirect reflections of the genes’ activity reach the phenotype of a person. (13.02.01 PM)

Mapping the genes will enable to cure genetic diseases with the help of genes. Such diseases are, for example, cardiac diseases, schizophrenia, hypertonic disease and cancer. (PM 27.06.00)

Genes determine the person’s character, physical appearance and diseases. ...As for the most common diseases such as cardiac disease, hypertonic disease, diabetes, and cancer, these are caused, to a great extent, by environment and the way of life. (27.06.00 EPL)

To a great extent, cancer is not a disease with heritable causes. Therefore, gene researchers admit the impact of environmental factors. However, cancer is

heritable at cellular level. This also determines the sensitivity of the person to environmental factors. (25.11.99. EPL)

Heritable diseases are rare. Cases of cancer which are caused by heritability, make up only 1% of all cases of cancer. (25.11.99. EPL)

As with homogeneity, there is again a variety of opinion and some terminological confusion. The first statement says all diseases are genetic; the second says not all, but most; it also distinguishes between genetic and heritable diseases. The third seems, in principle, to allow the possibility that perhaps there are no really genetic diseases at all. The fourth divides all diseases into two classes: genetic and nongenetic. So does the fifth, but most of the diseases which were, in the previous example, classified as genetic are now classified as non-genetic. The sixth statement is confused; it seems to say that cancer in some sense is not heritable; also, that in some other sense it is heritable; and that the extent to which cancer is nonheritable in the first sense is determined by factors which make it heritable in the second sense. The last statement speaks also about heritability and cancer, but the heritability it deals with is not the same as the heritability in the previous example. The previous statement seems to say that *any* case of cancer is “heritable at cellular level”, whereas the last says that only some rare cases of cancer are heritable (in some sense).

Part of the difficulties with this kind of statements derive from terminological confusions: genetic diseases are not the same as inherited (heritable) diseases. Unfortunately, they are not really distinguished in the discourse, these terms are rarely defined at all and are taken for granted. In fact, the same point probably applies to all technical terms used in the discourse. The importance of unambiguous terminology is something that is often stressed by scientists, philosophers and critics of the public discourse. To bring a recent example, Allen D. Roses (2000) discusses in his article in *Nature* the different meanings of ‘genetic testing’. His remarks on this issue seem directly relevant to the Estonian debates, but cannot be discussed here at any length.⁶ I shall bring only this general statement by Roses: “Clearly defined terminology should form the basis for

⁶ According to Roses, the term ‘genetic testing’ is currently used indiscriminately to refer to very different applications of genetic science. Even when limiting ourselves to one specific disease, say Alzheimer’s, one may imagine at least four kinds of possible genetic tests (some of them diagnostic, some pharmacogenetic). The important point is that the implications of all these tests for individuals and family members and societal risks of medical-care burden are very different. Genetic tests for mutations in single genes that are causally related to rare diseases and are inherited in simple mendelian fashion can have profound implications for individuals and family members. Genetic tests for susceptibility genes have the added complication of uncertainty. Pharmacogenetic profiles, on the other hand, will only predict if an individual is likely to benefit from a medicine and be free of serious side effects, giving no other information. The ethical, legal and social implications of these profiles are therefore of lower magnitude. The Estonian media discourse, in harmony with what Roses sees as a general situation, speaks simply of ‘genetic tests’, although it is likely that here also different kinds of tests are being talked about. This is probably one reason why the discussion of issues related to, e.g., genetic counselling has been very weak: the nature and costs of counselling are different with respect to different kinds of tests.

informative discussions so that the word ‘genetics’ is not demonized.... Language needs to be more precise so that there can be clarity, especially for public policy debates.”

However, accuracy in terminology will not solve all the problems, which are encountered when one tries to inform the public about the role of genes in diseases. Even if we confine ourselves to just one disease, e.g. cancer, the current state of research appears to be complicated and it is unclear how it might be possible at all to give any accessible and reliable information on this issue. In a recent book, former cell biologist and now philosopher of biology Lenny Moss gives a survey of the history of cancer research in the 20th century. His story is full of technical details, but basically it is one of competing models and ideologies. Here is one of his end conclusions

Twentieth-century biology has been guided largely by the heuristics of some form of genetic preformationism. .. Why then, at the end of the 20th century, when even the preformationist assumptions of the somatic mutation hypothesis are being progressively undercut, has a genomic model of heritable susceptibility to cancer emerged and even moved onto center stage?... Has gene-based heritability proven to play a greater role in the etiology of cancer than previously suspected? Certainly not.... The move from somatic mutation to genomic susceptibility ... reflects an unprecedented influence of the marketplace on the biomedical research agenda. (Moss 2002:182)

What this means, I think, is that even if one regards cancer as ‘genetic’, there are really different ways of conceptualising cancer as genetic. The model of somatic mutation operates with the concept of the gene; and the genomic model of heritable susceptibility also operates with the concept of the gene; these models are not necessarily in harmony, and they may lead to different methods of treatment and to different drugs. So, it is possible that talk of genomic susceptibilities (which evidently are discussed in connection with genetic databases) have to do with one specific genetic model of cancer – which in Moss’s opinion is not the one which is best confirmed or most promising at the present moment. Be it as it may, it is clear that the media discussions of cancer do not reflect anything of this; or if they do reflect something of this, they do so in an extremely opaque way.⁷

⁷ It is worth noting that Lenny Moss, when discussing different models of cancer, does not use words like ‘determinism’ or ‘causation’ at all, preferring to speak about different levels of analysis. One of the main tensions in cancer research he sees to be between subcellular and supracellular levels of analysis, or ‘gene-centered’ vs. alternative approaches. As to the Estonian media discourse, it is hard to say whether the idiom of causation and determinism, or the idiom of alternative analyses is more prevailing. It seems that most often one talks vaguely about the ‘geneticalness’ of diseases, traits *etc.*

For some other comments on the role of language in genetics, from various points of view, see Judson 2001, Lewontin 2001, Carroll 2001, Katz 2001. For some recent treatments on genetic determinism see Beurton *et al* 2000, Dawkins 2002, Griffiths 2003, Kaplan 2000.

8. Speculations, fears, fatalism

Fear is a word which seems ubiquitous in the Anglo-American public discourse on genetics. As to the Estonian debates, one cannot really say that the rhetoric of fear plays a prominent role here. Still, there are a few points worth mentioning. Talk about fears with respect to the database project is sometimes accompanied by general speculations on human nature or some more specific ethnopsychological (sociopsychological) suggestions. It has been said, for example, that being afraid of the databank has to do with the post-Soviet legacy; or that it is caused by the general tendency of human beings to be afraid of anything new. Occasionally, the fears are thought to be the outcome of the unfriendly activities of the opposition: "One uses the project of the gene bank to scare people and to divide the nation". (EPL 14.01.02)

One of the most extensive articles concerning the Estonian Human Genome Project is devoted specifically to fears (Lõhmus 2000). A journalist interviewed several well-known Estonian psychologists and psychiatrists, asking them about the possible sources of fears with respect to the database. The psychologists hypothesized a number of fears: fear to intervene with nature, fear to change the tradition, fear of evil genius, fear to lose control of one's fate, etc. Consulting psychologists may seem a reasonable move from the part of the journalist. However, this kind of investigations seem in principle misdirected. To use terminology of fear in the first place means to interpret the public in a certain way, to impose certain self-image on it. Fear and the person who fears something are often conceived as to some extent irrational, weak, or ridiculous. One can find instances of fear talk in the Estonian discourse where this kind of derogatory attitude is clearly felt. However, it is not at all sure that in the present case there really are any *fears* to speculate about. If there should be a sceptical attitude towards the project among people, it may well be one of rational mistrust. And when one faces the disagreement, confusion and contradiction in the database discourse, mistrust may be a natural and reasonable response. Moreover, psychoanalytic speculations are not testable. They are far less testable and as such far more uncertain than any uncertainties of the genetic research itself. Introducing doubtful speculations into an area of debate where there is already much confusion anyway is not at all helpful.

My other remark concerns fatalist rhetoric. The word 'fatalism' I use here to refer to any ideas of the sort that the course of history in general or some developments in the society are inevitable. This kind of ideas play some role in the rhetoric supporting the project.

We cannot escape development which is natural. (12.06.00 EPL)

We cannot escape introducing extensive genetic research: it is the requirement of time. (23.01.2001 PM)

The gene spirit has been let out of the Estonian bottle. One cannot push it back in. (15.12.00 PM)

The spirit has been let out of the bottle, one cannot block the progress of science. (09.08.00 EPL)

Part of such rhetoric may be developed into a philosophical claim which says that the progress of science and technology is a necessity. One version of this thesis, sometimes discussed in the academic philosophical discourse under the name of “technological determinism”, asserts that technological development has internal laws of its own and human choices or actions cannot change or control them. This is taken to mean, among other things, that all new technologies will be applied, no matter how problematic they are. Interestingly, this kind of claims can be used for contradicting purposes. In the bioethical discourse, one can find examples of how the thesis of technological determinism has been used by the *opponents* of gene technology.⁸ The logic then is that, since the development of technology is uncontrollable, one should ban problematic technologies, so that they would not get beyond control. In the Estonian debates, on the contrary, deterministic ideas are used by the proponents of the project: there is no sense in resisting technological progress because it will take place anyway.

9. Science and the public

The issue of the relationship between science and the public has not been really discussed within the context of the database discourse. There are some declarations to the effect that public debate is a good thing; also, one finds a couple of statements which sound a bit more resolutely and radically:

In Estonia, one should start a public discussion concerning priorities in health-care and science. (12.06.00 EPL)

In case of atomic physics and genetic technology, there is reason to be worried. More distant consequences cannot be predicted, therefore, genetics cannot be left to the geneticists. These things concern everyone. (17.04.02 EPL)

The scientist will not decide how far to go with genetics. This is society's business. (17.09.2001 EPL)

As it is the general relationship between science and the public which is of interest here, it is worth asking what kind of thing science is in general thought to be by the debaters. There are very few explicit statements on this issue. Once or twice, there occurs the idea that in science one is dealing with competing research programs. The idea that one and the same phenomenon (e.g. a particular disease) may be conceptualised in different ways within different paradigms of research, occurs only once – as does the idea concerning the (in)dependence of science on values (“science is value-neutral”). There is a statement I especially want to draw attention to:

I don't doubt that politicians and activists who furiously want to limit research on stem cells and in general the triumph of genetics, may win themselves the image of nobleness and rightness. Still, this is only populism, it is one more self-deception of the mankind. And as such it is ridiculous, it is even non-Christian.

⁸ See, for example, (Häyry 1994:149).

*... The brave Americans will probably ridicule themselves by their attempt to censor science. There was a time when Russia claimed to be the “gendarme” of Europe. Do they now have the intention, on the other side of the ocean, to become the “gendarmes of the world”?*⁹ (11.08.2001 PM)

This is a rather strong rhetoric for unlimited growth of science. In general, media discussions (but also private conversations) give the impression that in Estonia any ideas supporting extensive public regulation of science are at the present moment likely to be considered as outright horrible. Science seems to be perceived as a pure quest for objective truth, practiced by people wise and honest, and bringing benefits to us all. It is only some very special kinds of inquiry which need some cautious regulation. For the sake of contrast, the aforementioned forceful rhetoric against “censoring science” might be compared to a passage from Erkki Kauhanen’s work on Finnish science media; here is one of his end conclusions (Kauhanen 1997:340):

Thus, science is descending from the podium. People are generally realizing that just as there is bad house construction there is also bad science; ... in addition to questionable morals and motives in business, there are also people who have questionable morals and motives in their scientific activity. ... In short: science must be socially checked and controlled like any other social institution.

I don’t think that this kind of statements would be taken seriously by the Estonian public. It may of course be that such statements would not be taken so seriously by the Finnish public either; at least, European multinational empirical surveys indicate that the population of Finland is significantly more technophile than some other countries in Europe.¹⁰

Finally, in the Anglo-American discourse, there is a lot of talk about the negative image of science and scientists in the media. Again, a first glance at the database discourse makes one think that this may not apply to the Estonian media at all: rather, the image of science and scientists is overwhelmingly positive, and the database project may have benefited from this. However, these ideas concerning the perception of science by the Estonian public are speculative; to some extent, they could be empirically tested in the future, by the methods of discourse analysis or sociological research.

⁹ These statements may be found in an article by a well-known Estonian writer devoted to the banning of human cloning by the US House of Representatives. Strictly speaking, this article does not belong to the database discourse (it was not part of the sample which formed the basis of the present paper). However, there is perhaps reason to consider this declaration here, since the author is a member of the Ethics Committee of the Estonian Genome Project.

¹⁰ For example, according to the latest empirical research concerning attitudes towards biotechnology, the public in Finland seems to have a clearly more positive attitude towards such research than many other countries. A quote from a recent analysis based on the Eurobarometer survey of 1996: “Most inclined to encourage the use of genetic technology is Portugal, followed by other southern countries of the EU and the one furthest to the north, Finland. The common characteristic of these countries would seem to be their peripheral location to Central Europe.” (Midden *et al* 2002:207)

10. Failure of rational communication?

The participants of the database discourse have themselves assessed the situation in the debates variously:

The number of people who know nothing about the genes is getting smaller all the time. I do not quite agree that there has been no debate. There has. At least the basic concepts have been conveyed to the people. (03.05.2001 EE)

A great part of the population has understood the project. In a poll conducted by EMOR, only 6% of respondents clearly opposed the database. (14.01.2002 EPL)

There has been more propaganda than informing. .. The debates have been very weak. One gets the impression of shameless manipulation. (27.09.01 EE)

As to my own assessment, it seems fair to say the following. Something like an attempt to inform (or to become informed) of the scientific rationale of the database project was apparently made in the Estonian media, but the result is disappointing. Ill-defined terms, claims which are hard to interpret, and conflicting expert opinions make it hard if not impossible for the general reader to form a reasonable opinion of the project. Moreover, some possibly problematic aspects of the project, like the methodology of phenotyping, which at expert gatherings has often been seen as the greatest obstacle, have hardly been mentioned in the media discourse at all.

The second of the above-mentioned statements deserves a separate comment. It links knowledge and attitude, being a version of a common hypothesis in science communication – the so-called knowledge deficit model – which says, roughly: “knowledge breeds love, ignorance breeds contempt. Therefore, people who challenge science and technology, must be ignorant.”¹¹ This is an idea that occurs more than once in the Estonian database context also. A recent example is the statement by the Head of Information of the Estonian Genome Project Foundation (Koik 2003): “In general, the attitude of Estonian and foreign media towards the Genome Project is positive. However, there have been a few sceptical analyses, which can be attributed to the fact that the field of genetics, genes and biotechnology is new to the authors of those analyses. They have failed to grasp either the true nature or future plans of the Genome Project.” (The same statement also refers to EMOR surveys which have revealed that “65% of the population of Estonia is well-informed about the Estonian Genome Project.”) This simple relation between knowledge and attitude – more knowledge means more positive attitude – is not necessarily confirmed by empirical data. To mention but one

¹¹ Several articles in (Bauer and Gaskell 2002) touch upon the knowledge deficit model. In the context of the present paper, the so-called knowledge gap hypothesis may also be of interest. The underlying assumption of this hypothesis is that a mere increase in information will not automatically result in a better and more equally informed public. Instead, the well educated segments of society are able to use the media more efficiently than the less well educated. As a result, the knowledge gaps between different social segments will increase rather than decrease. In other words, “information dissemination conforms to the ‘Matthew principle’: those who have it will be given more” (Bauer and Bonfadelli 2002:152).

recent study, Allum et al. (2002) have suggested, and found some corroboration for, the idea that the aforementioned relation is characteristic of an industrial society, whereas in more developed, post-industrial mode the relationship between knowledge and attitudes becomes more complex.

Here, I would like to return for a moment to the three theses of science communication mentioned at the beginning of this paper:

- The public gets most of its information about science from the media.
- The public is ignorant about science.
- The media are unable to communicate science effectively.

In this particular case of the Estonian database, I think the ignorance of the public cannot be said to play any role in the failure of communication, in the sense that a moderately knowledgeable reader will confront as great difficulties as a quite ignorant one. Knowing that there are genes in the food, or knowing the chemical details of the DNA will be of no big help, when trying to assess the perspectives of the databank project – because scientific knowledge which really might help to understand this project is of a very specific and technical kind. Also, it would be strange to expect that the methodologies of finding susceptibility genes, the perspectives of different models in cancer or schizophrenia research, or the intricacies of genetic determinism might be taught to people at high school or explained in a pub; however, something like this – “going to the schools” and “introducing gene pubs and gene trains, as have done some countries in Europe” (14.01.02 EPL) – has been suggested by some promoters of the project.

As to the inability of the media, this seems to be a fact. However, although the media have failed to communicate anything about the science behind the project, it is not certain that this has to be attributed to the especially bad performance of journalists. In some respects, the media have not performed badly: it is questionable whether there has been any real journalistic distortion; one finds almost no trace of sensationalism, which in the Anglo-American discourse is often seen as the greatest sin of science media; and the newspapers have not been afraid of publishing boring things (for example, the unexciting details about transport and security procedures have been laid out thoroughly and repeatedly). Had there been any serious treatments of the issues related to homogeneity or the causal role of genes available, they would probably have appeared in the media. If they did not appear, this perhaps means they were simply not written.

Leaving the Estonian context aside for a moment, I suggest that two general questions are worth posing: whether it is at all *possible* to really inform about scientific technicalities through the mass media; and whether it is at all *necessary* to inform the public about such technicalities. There are people who think that any kind of knowledge or information is inherently valuable, that information is a good in itself, and that there should be as much of this good as possible. Also, in discussions on biotechnology, one sometimes finds declarations like “a well-informed public is imperative for the effective functioning of modern democracy”, or something like that. However, the idea of informing people about *everything* cannot be taken seriously. To invoke a simple metaphor, being acquainted with the

technical details of a car engine is usually not considered a necessary condition for participating in street traffic – one has to trust the engineers and technicians. Perhaps informing citizens about the rationales and methodologies of scientific projects is something similar. Although it would be nice in principle, if an ordinary citizen (and a potential gene donor) knew all about the genetic profiles of Estonia or Sardinia, or about competing theoretical models concerning disease or biological causality, this simply cannot be accomplished. However, another traffic metaphor is also possible. Namely, if anyone wants to seriously participate in deciding what kind of cars should be present in the streets, the technical details of the engines cannot be ignored any more; despite all the difficulty, one has to find a way to inform and to become informed of these details. Whether the database case is better described by the first or the second metaphor, is not easy to say. In any case, it seems likely that in the case of the Estonian database no one, neither the initiators of the project nor the public itself, seriously believes that the public should participate in decision-making concerning this project. If so, one essential motive for adequate informing gets lost.

11. Some recent developments in theoretical and practical science policy

I shall now very briefly consider the idea that has to do with the second ‘traffic metaphor’: the public should not only be informed – it should also directly participate in the process of decision-making, when large-scale or otherwise significant scientific projects are involved. The idea of the democratisation of science policy seems quite new even in the European and US context (probably not older than a decade or two).

At the practical level, since the beginning of the 1990s some countries in Europe (Denmark, the UK, Netherlands) and the US have experimented with new kinds of public consultation in science policy. The aforementioned SCST report by the UK House of Lords Committee lists altogether ten such forms of consultation. Some of these forms are really close to market research exercises, but some are directed towards the ideal of direct democracy. In this latter connection, one most often refers to ‘consensus conferences’, sometimes also to ‘citizens’ juries’. The first consensus conferences were organized by the DBT (Danish Board of Technology) and they had some real impact on government policy. However, the DBT itself did not see its work with the public as “direct democracy”: the results of its work were made available for the Danish Parliament to use as it saw fit. In Great Britain, there have been at least two such conferences (in 1994, on GM plants; in 1999, on nuclear waste management). The SCST report sees them as positive experience, but is not sure whether they had any real impact. The Commission of the European Communities comments on such developments in its working document in the following way:

Their use has illustrated the extent to which ordinary members of the public, once they have all the information in their possession, can conduct high-quality

dialogue with experts, put judicious questions to these experts, deliver balanced judgments and reach a reasonable consensus. (Commission of the European Communities 2000, paragraph 4.1)

However, the Commission's overall attitude towards such initiatives is not very enthusiastic. In its opinion, such consultation forms can in no way replace democratic debate in its traditional forms, and still less the political decision-making process. They can only help the debate to unfold and to aid decision-making. The attitude of the British SCST report is much more radical and as such has attracted a lot of attention. Several recent studies and surveys on biotechnology issues in the UK refer to this document; also, the British Government and the Royal Society have reacted to it (The Royal Society 1999). The report declares that it is time to change the mechanism of decision-making in science policy: informing is not enough, what one really needs is the participation of the public in decision-making processes. As compared to the EC document, it is said about the aforementioned experiments:

They are however isolated events and no substitute for genuine changes in the cultures and constitutions of key decision-making institutions. ... It is required to go beyond event-based initiatives like consensus conferences or citizens' juries. A radically different approach to the process of policy-making in areas involving science is called for. (Introduction, p. 4–5.)

When moving at the level of these practical developments and political documents, it seems clear that the ideas concerning the possible democratisation of science policy are not founded on any definite philosophical conception of science. Implicitly, however, some such account must be there. If it is science that is to be regulated, one must have some ideas as to what kind of thing science is. From the SCST report, for example, one can extract the following, embryonic philosophy of science:

1.1. By "science" we mean the biological and physical sciences and their technological applications.

1.2. In scientific research, the frontiers of knowledge are advanced in most cases by observation and by the experimental testing of hypotheses.

1.5. Science embraces engineering, technology and medicine. In all these disciplines there are elements of pure science; medicine, e.g., takes in physiology, pharmacology and genetics. Most science, however, is applied to real-life problems, and is used to design and produce things that are of use, for good or for ill.

2.65 In our view knowledge obtained through scientific investigation does not in itself have a moral dimension, but the ways in which it is pursued, and the applications to which it may be put, inevitably engage with morality.

This conception is vague with respect to several essential points. No sharp line is here drawn between science and technology, or between pure and applied science – but some kind of line is still drawn. The possibility that there exists some pure science is allowed – but most science is not pure. Observation and testing are important; but it is not ruled out that, for example, creative theoretical construction

also plays a vital role. Scientific knowledge in itself does not have a moral dimension; but is this the same as to say that it is value-neutral? These are all issues in philosophy of science which have been hotly debated by philosophers for at least the last 50 years already.

At the theoretical level, philosopher of science Philip Kitcher (2001) has recently offered a very radical model of democratic science policy – the ideal of “well-ordered science”, modelled on John Rawls’s “well-ordered society”. Kitcher’s model is explicitly founded on a particular conception of science which is in some sense a “middle way” between the extremes found in philosophy of science – those who see scientific knowledge as social construct and those who believe that science is an autonomous and entirely rational pursuit of objective truth. To mention some crucial points in Kitcher’s account: all science is an assemblage of particular research programs; these research programs are not necessarily in harmony, nor is any of them *a priori* privileged; perhaps most importantly, every research program is necessarily situated in a specific context of epistemic and practical interests. At the same time, within its particular context, knowledge obtained by a research program can be said to be (in some specific sense) objective, and not a social construct. As said, this is a moderate philosophy of science. But the point about any scientific research being situated in the context of particular epistemic and practical interests is actually enough to ground the idea of democratic science policy.

To add one further point for clarification, according to Kitcher, there are four principal ways in which research agendas may be set:

- internal elitism (decision-making by members of scientific sub-communities)
- external elitism (decisions made by scientists and privileged outsiders, those with funds to support research – the “paymasters”)
- vulgar democracy (decisions made by a group that represents some of the diverse interests in the society with advice from scientific experts)
- enlightened democracy (decisions made by a group that receives tutoring from scientific experts and accepts input from all significant perspectives in the society)

The *status quo* in affluent democracies is, on Kitcher’s view, a situation of external elitism that groups of scientists constantly struggle to transform into a state of internal elitism. As to vulgar democracy – “this is likely to be a bad idea. The interesting question is whether enlightened democracy would be preferable to either form of elitism” (Kitcher 2001:133). Kitcher’s answer to this latter question is ‘yes’; and he tries to give a first outline of the procedures of the ideal body of science deliberators. In the context of this paper, it is important to note that ‘tutoring from scientific experts’, a requirement of enlightened democracy, involves much more sophisticated informing procedures than is usual now.

Another significant theoretical contribution in this field is the programmatic article by Harry Collins and Robert Evans (2002), which is presented from the perspective of the sociological wing of science studies. These authors focus on the

concept of 'technical decision-making' that is defined as 'decision-making at those points where science and technology intersect with the political domain because the issues are of visible relevance to the public'. On Collins's and Evans's view, the predominant motif over recent years has been the need to extend the domain of technical decision-making beyond the technically qualified elite. As they see it, there is even a tendency (among sociologically-minded theoreticians) to dissolve the boundary between experts and the public so that there are no longer any grounds for limiting the indefinite extension of technical decision-making rights. Collins and Evans disagree with this. Their proposal is to work out a normative theory of expertise which would significantly but not indefinitely extend the notion of an 'expert'. To mention again only some details: among other things, one should introduce the concept of 'interactional expertise'. An interactional expert is a person (or a body of persons) who is able to translate between scientist and the public – a role which might be played by a sociologist of science, for example (rather than a journalist). In a way, the activity of such experts might be complementary to the PR-activities of the scientists themselves. Also, institutions are needed that can translate the knowledge of the 'pockets of experience-based expertise' (such as the experiential knowledge of farmers about environmental and ecological issues, or the experiential knowledge of medical patients about their specific disease) so as to make it is less easy for certified scientists to resist their advice. In fact, the authors think that such bodies of experts already exist, but tend to be associated with campaigning organizations.

It is clear that the practical and theoretical developments considered above have something to do with such projects as the Estonian Human Genome Project. This is not altered by the fact that the project is more or less a private enterprise, not funded by the state. Kitcher's theory as well as Collins's and Evans's account both regard science and technology as ventures which have immense impact on many aspects of life, and therefore, they do not really distinguish between privately and publicly funded science. Of course, these theories are controversial and may be expected to give rise to many debates within philosophy and sociology of science itself.¹² Even if accepted, it is not clear when, how and to what extent these theories can be applied. Taking once more the case of the Estonian genetic database, what might the extension of the concept of an expert mean here? Would such an extension be reasonable? On the one hand, the database project definitely deals with 'issues that are of visible relevance to the public' and qualifies as public (as opposed to esoteric) science, so that the involvement of the general public in decision-making is justified; but can we, for example, speak of any 'experience-based pockets of expertise' here? What might these be? Also, if some biomedical researchers or general practitioners oppose the project on the grounds that they do not believe in the causally decisive role of the genes in the etiology of diseases,

¹² For some responses and criticisms concerning Kitcher's theory, see Goodstein 2002, Strawson 2002, Lewontin 2002, Longino 2002, Kitcher 2002. As to Collins's and Evans's theory of expertise, the journal *Social Studies of Science* will devote one of its next issues to an extensive discussion of this theory.

who might be the 'interactional expert' (or what might be the relevant institutions) whose task would be to translate their worries into the language understandable to the promoters of the project?

12. Conclusions

In general, the **Estonian** media debates on the proposed nation-wide genetic database appear to present a case of failure of rational communication, at least insofar as the scientific aspects of the project are concerned. Pro-science rhetoric and pseudoargument play a more prominent role than informative discussion. It is hard to believe that a non-specialist, however educated and reflective, can obtain any significant help from the media when trying to form a considered opinion on the project. In part, this may be due to some specific circumstances (for example, the lack of professional science journalists, or the business and PR-interests of those involved in the project); however, it is also possible that even with the best efforts of journalists and scientists, the mass media simply are not the right forum for discussing such technically complex issues. This does not necessarily mean that scientific issues cannot be discussed with the public at all. Recent European and US experiments in practical science policy as well as the latest theoretical developments by philosophers and sociologists of science make it likely that, in the years to come, other forms of public involvement in science besides media debates will acquire an ever-increasing importance. In addition to the promotion of the idea of direct democracy, the procedures of consensus conferences and similar events could give better opportunities for discussing the technicalities and ideologies of scientific projects. As to the image of science, the Estonian media material gives reason to hypothesize that the science is understood by the Estonian public too simplistically and in excessively positive light. To confirm or disconfirm this, further research involving discourse analysis and sociological studies may be necessary.

Acknowledgement

This paper was produced as a part of the ELSAGEN project (Ethical, Legal and Social Aspects of Human Genetic Databases: A European Comparison), financed between 2002 and 2004 by the European Commission's 5th Framework Programme, Quality of Life (contract number QLG6-CT-2001-00062). I gratefully acknowledge the support of the European Community. The information provided is the sole responsibility of the author, the Community is not responsible for any use that might be made of data appearing in this publication. I gratefully acknowledge the support of the Nordic Academy for Advanced Study (NorFa) and the NorFa Network The Ethics of Genetic and Medical Information.

Address:

Tiiu Hallap
 Department of Philosophy
 University of Tartu
 Lossi 3
 50090 Tartu, Estonia
 Tel.: +372 7410 300
 E-mail: hallap@hot.ee

References

- Allum, N., D. Boy, and M. W. Bauer. 2002 "European Regions and the Knowledge Deficit model". In *Biotechnology – The Making of a Global Controversy*. M. W. Bauer and George Gaskell, eds. 225–243, Cambridge: Cambridge University Press.
- Bauer, M. W. and H. Bonfadelli. 2002 "Controversy, Media Coverage and Public Knowledge". In *Biotechnology – The Making of a Global Controversy*. M. W. Bauer and George Gaskell, eds. 149–175, Cambridge: Cambridge University Press.
- Bauer, M. W. and G. Gaskell, eds. 2002 *Biotechnology – the Making of a Global Controversy*. Cambridge: Cambridge University Press.
- Beurton, P., R. Falk, and H.-J. Rheinberger, eds. 2000 *The Concept of the Gene in Development and Evolution*. Cambridge: Cambridge University Press.
- Carroll, S. B. 2001 "Communication Breakdown?" *Science*, Vol. 291, 16 February 2001, 1264–1265.
- Collins, H. M. and R. Evans. 2002 "The Third Wave of Science Studies: Studies of Expertise and Experience". *Social Studies of Science*, vol. 32, No 2 (April), 235–96.
- Commission of the European Communities. 2000. *Science, Society and the Citizen in Europe*. Commission Working Document. Brussels.
- Condit, C. M. 1999 *The Meanings of the Gene. Public Debates about Human Heredity*. Madison: The University of Wisconsin Press.
- Dawkins, R. 2002 "Genetic Determinism and Gene Selectionism". In *Companion to Genethics*. Justine Burley and John Harris, eds. 253–270, Oxford: Blackwell.
- Durant, J. R., G. A. Evans, and G. P. Thomas. 1989 "The Public Understanding of Science". *Nature*, vol. 340, 6 July 1989, pp. 11–14.
- Durant, J. R., J. D. Miller, J.-F. Tschernia, and W. van Deelen. 1991 "Europeans, Science and Technology". Paper presented to the annual meeting of the American Association for the Advancement of Science, Washington D.C. February 15, 1991.
- Gilbert, G. N., and M. Mulkay. 1984 *Opening Pandora's Box: A Sociological Analysis of Scientists' Discourse*. Cambridge: Cambridge University Press.
- Goodstein, D. 2002 "Setting Scientific Agendas". *American Scientist*. March-April 2002.
- Griffiths, P. E. 2003 "The Fearless Vampire Conservator: Philip Kitcher on Genetic Determinism". In *Genes in Development*. E. M. Neumann-Held and C. Rehmann-Sutter, eds. Duke University Press. (in press)
- Häyry, H. 1994 "How to Assess the Consequences of Genetic Engineering?" In *Ethics and Biotechnology*. A. Dyson and J. Harris, eds. New York: Routledge.
- Irwin, A., and B. Wynne, eds. 1996 *Misunderstanding Science? The Public Reconstruction of Science and Technology*. Cambridge: Cambridge University Press.
- Judson, H. F. 2001 "Talking about the Genome". *Nature*, Vol. 409, 15 February 2001, p. 769.
- Kaplan, J. M. 2000 *The Limits and Lies of Human Genetic Research*. New York: Routledge.
- Katz, S. B. 2001 "Language and Persuasion in Biotechnology Communication with the Public: How to Not Say What You're Not Going to Not Say and Not Say It". *AgBioForum*, Vol. 4, No. 2, pp. 93–97.

- Kauhanen, E. 1997 *The River of Ink. Media Epistemology, Ontology and Imagology in the Light of Science, Pseudoscience and Technology Material in 6 Major Finnish Newspapers in 1990. A discourse analytical study.* Helsinki 1997.
- Kitcher, P. 2001 *Science, Truth, and Democracy.* Oxford: Oxford University Press.
- Kitcher, P. 2002 "Reply to Helen Longino". *Philosophy of Science*, Vol. 69 (December), pp. 569–72.
- Koik, A. 2003 "The Estonian Genome Project: a Hot Media Item". *OpenDemocracy*, 7 July 2003 (available on-line at <http://www.geenivaramu.ee>).
- Lewontin, R. C. 2001 "In the Beginning was the Word". *Science*, Vol. 291, 16 February 2001, pp. 1263–1264.
- Lewontin, R. C. 2002 "The Politics of Science". *The New York Review of Books*, May 9, 2002.
- Longino, H. E. 2002 "Science and the Common Good: Thoughts on Philip Kitcher's". *Science, Truth, and Democracy. Philosophy of Science* Vol. 69 (December), pp. 560–68.
- Lõhmus, A. 2000 "Ohoo, teie geenid tuleb ümber teha! Kas meil on põhjust oma geene karta – ja kui, siis miks?" *Arter*, 23.09.2000
- Macer, D. R. J. 1992 *Attitudes to Genetic Engineering: Japanese and International Comparisons.* Christchurch: Eubios Ethics Institute.
- Martin, J. R., and R. Veel, eds. 1998 *Reading Science. Critical and Functional Perspectives on Discourses of Science.* London: Routledge.
- Metspalu, A. 2003 E-mail note to the author from 31.01.2003.
- Midden, C., Boy, D., Einsiedel, E., Fjæstad, Liakopoulos, M., Miller, J. D., Öhman, S. and W. Wagner. "The Structure of Public Perceptions". In *The Making of a Global Controversy.* M. W. Bauer and George Gaskell, eds. 203–224, Cambridge: Cambridge University Press.
- MORI and Wellcome Trust. 2000 *The Role of Scientists in Public Debate.* Research study conducted by MORI for the Wellcome Trust. December 1999 – March 2000.
- Moss, L. 2002 *What Genes Can't Do.* Cambridge: The MIT Press.
- Pálsson, G. and K. E. Harðardóttir. 2002 "For Whom the Cell Tolls. – Debates about Biomedicine". *Current Anthropology*, Vol. 43, No. 2, April 2002, pp. 271–301.
- Pálsson, G. and P. Rabinow. 2001 "The Icelandic Genome Debate". *Trends in Biotechnology*, Vol. 19, No. 5, May 2001, pp. 166–171.
- Rose, H. 2001 *The Commodification of Bioinformation: The Icelandic Health Sector Database.* Published by The Wellcome Trust, London.
- Roses, A. D. "Pharmacogenetics and the Practice of Medicine". *Nature*, Vol. 405, 15 June 2000, pp. 857–865.
- Select Committee on Science and Technology, House of Lords, UK. February 2000 *Third Report on Science and Society.*
- Strawson, G. 2002 "Improving Scientific Ethics Through Democratization". *New York Times*, January 20, 2002.
- The Royal Society. 1999 *Science and Society.* A response from the Royal Society to the House of Lords Science and Technology Select Committee Inquiry.
- Tamppuu, Piia. 2003 "Constructing Images of New Genetics and Biotechnology in the Public: The Public Discourse on Estonian Human Genome Project". *Trames*,