EUROPEAN GROUP ON ETHICS
IN SCIENCE AND NEW TECHNOLOGIES TO THE EUROPEAN COMMISSION

GENETIC TESTING IN THE WORKPLACE

Proceedings of the Round Table Debate held at the Borchette Center, Brussels

6 March 2000

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Preface

The European Group on Ethics in Science and New Technologies (EGE) is an independent multicultural and multi-disciplinary body, composed of twelve experts representing a variety of viewpoints and disciplines.

The EGE has been set up by decision of the European Commission of December 1997 to advise the European institutions on the ethical aspects of European regulatory activities or policies.

The field of competence of the EGE covers biotechnology as well as communication and information technologies.

In preparing its opinions, the EGE is open to broad consultation, involving experts as well as representatives of civil society.

A round table was organised by the EGE in Brussels on March 6th 2000 on "Genetic Testing in the Workplace", as the Group is preparing an Opinion on that issue to be published in the beginning of 2001.

It raises not only the ethical issues related to genetic testing and predictive medicine in general, but also the ethical issues related to the principle of justice and non-discrimination in access to work.

Furthermore, the issue of genetic testing at the workplace has a particular European dimension as workers can freely cross borderlines within the European Communities.

The Minutes of this round table will thus constitute a valuable element of the ongoing discussion on genetic testing at the wor place.

Noëlle LENOIR
President of the European Group on Ethics
in Science and New Technologies (EGE)

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XXVIIth MEETING OF THE EUROPEAN GROUP ON ETHICS IN SCIENCE AND NEW TECHNOLOGIES (EGE)

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Karel VAN DAMME
MD, Center for Human genetics
University of Leuven, Belgium

Genetic testing in the workplace: the scientific aspects

Mr Karel Van Damme is medical doctor, specialised in occupational health and epidemologist. He is Director at the Medical Labour Inspectorate, Belgian Ministry of Employment and Labour;
President of the Belgian Fund for Occupational Diseases, one of the federal social security institutions;
Visiting scientist at the Center for Human Genetics, University of Leuven, Belgium;
Fellow at the University of Antwerpen, Department of Epidemology and Community Medicine, Belgium;
Fellow of the Collegium Ramazzini;

Member of the ICOH (International Conference on Occupational Health) Scientific Committee on Ethics in Occupational health, dealing with "The International Code of Ethics for Occupational Health Professionals";
Co-ordinator of several European and Belgian inter-university research projects, a/o. project co-ordinator EEC Concerted Action (BMH1-CT92-1213) „Ethical, social and scientific problems related to the application of genetic screening and genetic monitoring for employees in the context of a European approach to the health and safety at work“ (1992-1996/260.000 at the Center for Human Genetics-University of Leuven);

Mr Van Damme's research reports and papers cover namely the follwing fields: causes of myelodysplastic syndrome; exposure related genomic lesions; genetic susceptibility for benzene induced health effects; causes of newborn leukemia; occupational cancer; occupational exposure limit values; scientific and socio-ethical analysis of medical testing practices.

Introduction:

The ethical debate on the acceptability of genetic testing practices in occupational health may considerably benefit from a thorough understanding of the possible relevance or irrelevance of genetic testing in the workplace.

Altough many correlations between a particular genetic test result and the risk for a particular disease are being demonstrated, the predictive value of genetic testing for disease occurrance at the individual level is weak for most diseases, including occupational diseases. This is so because disease occurance in an individual is usually the result of very complex interactions of many genes and the environment. Only in the case of genetic determinism, disease prediction is or will be possible and completely reliable. This is the case for instance in Huntington disease, where one single gene disorder inevitably leads to disease. However, determinism is the great exception. In that case, environmental factors will not affect the outcome. In all other cases, we have to deal with probabilities, not certainties.

In occupational health research, associations have been demonstrated between particular genetic test results and disease occurance, especially with respect to cancer risk following particular exposures. The best known example is the risk of developing bladder cancer following exposure to benzidine, a substance which is now forbidden. Several epidemiological studies showed an association while some did not. This inconsistency could be explained for instance by differences in level of exposure to benzidine in different studies (at elevated levels of exposure, the 'relative risk' may increase or decrease –it is not known- for the persons having the 'wrong gene') and by differences in exposure to other interfering factors, which have not been identified. This may illustrate why a 'relative risk' or a 'probability' which is assessed in one study cannot simply be extrapolated to other situations.

But even apart from these considerations, the **possible relevance of genetic testing - as of other testing for predicting or preventing disease in the workplace - is not an intrinsic property of these tests but is largely affected by the context of the testing practice**: why is it done and who does it are two of the key questions in this respect. In order to answer these questions, key goals and objectives in occupational health practices and the professionalism and role of occupational health practitioners required to meet these goals and objectives have to be identified.

Tools and objectives in occupational health policies and practices

Tools in occupational health practices are related to

- the surveillance and adaptation of workplaces, tasks and working conditions;
- pre-employment and pre-placement testing practices and
- medical/health surveillance of workers both at regular intervals and problem related.

The ways in which these three sets of tools are used and their complementarity will be defined by the basic options and objectives of occupational health policies. Direct or indirect options and objectives could be to allow employment whilst protecting health on the one hand, or to reduce absenteeism, reduce insurance cost and increase productivity on the other. The first option requires a preventive approach to occupational health, while the latter three are believed to be better served through what could be called a predictive approach. In figure 1 the former is described as a *'health and employment protection approach'*, and the latter as a *'standardisation approach'* (see also annex 1). The figure represents a model which should clarify the nature of the ongoing shift towards the (new wave) standardisation approach to occupational health within the European Union. .

The standardisation approach, which is apparently connected with the principle of the free circulation of goods and workers, fails to take into account that individuals differ greatly and that a standardised worker does not exist. The theoretical complement of such an approach is therefore inevitably to focus on *selecting out* those persons who are considered not to comply with the standards, for instance those who are considered as more vulnerable than the 'average' (for instance following predictive genetic testing) at the pre-employment examination or following any indication of a possible increased risk of an exposure -related adverse health effect at the time of periodical health surveillance. A standardisation approach stands for a reductionistic approach to health and may easily lead to consequences which contravene the principle of social protection.

In contrast, the health and employment protection approach focuses on the interaction between worker(s) and working conditions at the pre-employment examination with the aim of employing every candidate whilst protecting his/her total health. Periodical medical surveillance is used with a view to monitoring and protecting total health. This approach is in accordance with social justice principles.

In accordance with social justice principles, **the basic goal of occupational health policies should be to contribute to resolving conflicts between values such as the need for health protection and the right to work, at the level of both the individual and all workers, with the aim of protecting health and allowing employment.** This implies that the guiding principle of occupational health policies and for occupational health professionals —physicians and others— should be to contribute to improving workplaces and adapting tasks such that virtually any worker who has the necessary skill could perform the job safely and without endangering their health on the one hand, and to contribute to maximising the opportunity for each individual worker to be offered a proper job on the other. The complement of such a guiding principle would of course be to aim to avoid employing workers in jobs that would certainly be detrimental to their health.

These guiding principles have to a large extent directed occupational medicine, its regulations and practices in most EU Member States during the last few decades. The International Code of Ethics for Occupational Health Professionals, an ICOH (International Commission on Occupational Health) document can be considered as the expression of the 'best practices' in this respect, and clearly meets the social justice principles. It is worth mentioning that this is one of the rare international reference documents which explicitly address pre-employment practices and policies[1].

Genetic testing in occupational health

Genetic screening and genetic monitoring are new (possible) tools in occupational health. Genetic testing is still used mainly for research purposes, but its use on a routine basis might represent a challenge to current prevention policies. Genetic biomonitoring must be distinguished from genetic screening for genomic properties.

[1] It should be obvious that pre-employment practices are an excellent reference point for assessing the de facto aims and objectives in occupational health practices. However, international declarations related to occupational health often do not deal explicitely and directly with pre-employment testing procedures. It seems as if workers rights are not covered by labour regulations prior to employment. One of the exceptions in this respect was a Recommendation from the Council of Europe, in casu the No. R (92)3 of the Committee of Ministers to Member States, on Genetic Testing and Screening for Health Care Purposes (1992):

"Principle 6. Non-compulsory nature of tests

a. Health service benefits, family allowances, marriage requirements or other similar formalities, as well as the admission to, or the continued exercise of, certain activities, especially employment, should not be made dependent on the undergoing of genetic tests or screening. Exceptions to this principle must be justified by reasons of direct protection of the person concerned or of a third party and be directly related to the specific conditions of the activity.

b. Only if expressly allowed by law might tests be made compulsory for the protection of individuals or the public."

*Genetic Monitoring:

Our understanding of toxicological processes at the molecular level has increased rapidly. Conventional biological monitoring for early indicators of dose and/or possible adverse health effects (like lead concentration in blood, liver enzymes in toluene exposed workers, peripheral blood cell count in benzene exposed workers) has been bolstered by the new tools of genetic monitoring and molecular toxicology. **Genetic biomonitoring** involves a series of specific techniques for assessing risk associated with exposure to genotoxic compounds (which may affect the chromosomes and their genes), through measuring biomarkers of biologically effective **dose** (like DNA adducts) or early biological **effects** (like chromosomal abberations) **in individuals with defined exposure** at work, in the environment or from their lifestyle. Peripheral blood lymphocytes –a type of white blood cells- are often used for this, because the findings in the chromosomes of these cells may give a representative indication of the dose or effect in an individual's whole body and because these cells can be collected from a simple blood sample. Genetic monitoring can potentially result in early identification of genotoxic exposures and thus enable the identification of high risk populations and of priorities for intervention. Use of early biomarkers can save time and might be relevant to prevent more serious end-effects, such as cancer.

Although most known carcinogens induce damage in lymphocytic chromosomes the number of agents repeatedly shown to induce damage in lymphocyte chromosomes is still relatively limited. Most of the experience gained in cytogenetic biomonitoring derives from situations of high occupational exposure. The extent of damage is a function of exposure level (dose-response relationship) as shown with, for example, vinyl chloride, benzene, ethylene oxide and alkylating anticancer agents.

Genetic biomonitoring could be used as part of **medical surveillance of workers.** Monitoring may be focused mainly on detection of the effects of exposures at the workplace; its results at the group level could aid in the identification of (unexpected) hazards and indicate actions that should be taken to reduce the hazardous exposures further or eliminate them. Even if these tests have mainly been used for research purposes and their results *interpreted at a group level with a view to identifying exposure to carcinogens*, results of such testing may either reflect individual susceptibility, or a positive result might be *considered as revealing increased susceptibility* (rightly or wrongly) and be used for that purpose as a kind of 'phenotype test' (see further under genetic screening). It should be stressed that the possible *relevance of the tests will not be the same in both applications*.

Positive results in human genetic monitoring are considered to be highly relevant for classifying human cancer risk by the International Agency for Research on Cancer (IARC). From both occupational or public health and scientific viewpoints, there should be increased integration of experimental techniques with epidemiological research strategies, in order to focus more effectively on cancer risk assessment. This will require collaborative, multidisciplinary research work among experts in different disciplines, before even considering the possible use of genetic biomonitoring on a routine basis in medical surveillance of workers.

*Genetic screening

Genetic screening involves testing to examine the **inborn** genetic characteristics that might confer relatively increased susceptibility for particular diseases. Each of our approximately 80.000 billion somatic (non-reproductive) cells have the same genome: 46 chromosomes with their total of several tenthousends of genes (reproductive cells like egg cells or sperm cells have 23 chromosomes).

Rapid progress in characterising the human genome, together with advances in molecular genetic techniques, is believed to increase the possibility of identifying relevant inherited susceptibility genes through correlation studies for many diseases **in healthy, asymptomatic individuals**.

Three models of genetic susceptibility factors can be identified:

- one based on genetic determinism without a role of external risk factors, e.g. Huntington's disease; persons having the 'wrong gene' will inevitably develop the fatal clinical neurological disease between the age of 30 and 50.
- one based on relative susceptibility to an external risk factor: non-carriers may be susceptible, but carriers of a particular variant of a gene are more vulnerable, both having a dose-related risk; difference in risk between carriers and non-carriers may vary with level of exposure. An example of this may be the 'genetic risk factor' of oat cell carcinoma of the lung due to cigarette smoking, where a japanese study demonstrated that the difference in risk is smaller (!) at higher levels of tobacco consumption; and
- one based on absolute susceptibility to an external risk factor: people without the genetic risk factor are not susceptible, while those with it have a dose-related risk for disease. It is possible that the risk for silicosis (coal miners lung disease) is somewhat closer to this model than to the previous.

Genetic tests that fit the first susceptibility model (determinism) have nothing to do with occupational health risk. Some of the genetic tests that fit the second and third models like genetic susceptibility to breast cancer, or diabetes or hypercholesterolemia have no direct relationship with either job fitness or susceptibility to occupational diseases, while other tests could be related to occupational exposure.

Genes are coding for proteins. Some of these proteins are enzymes involved in the metabolism of chemicals entering the body (xenobiotics). Variants of these genes can be identified for different subgroups of the population, which may reflect differences in metabolic transformation (for instance 'acetylation') of chemicals to which people are exposed, like drugs or industrial chemicals. Differences in transformation may result in differences in risk for adverse health effects with the same dose of dangerous substance absorbed.

In relation to carcinogenesis in particular, identification of the role of tumour suppressor genes and proto-oncogenes will clarify differences in susceptibility to cancer. Research in this field is concerned with defining the modulating role of genetic metabolic polymorphisms, i.e. the different abilities of subjects to activate or deactivate carcinogens to which they are exposed. Genetic metabolic polymorphisms were initially identified by measuring the phenotypic expression of a genotype; an example of phenotype testing is to apply a drug to individuals and to measure the rate at which it disappears from the body fluids, allowing for instance to distinguish between so called 'slow' and 'fast' acetylators. New genetic techniques now allow direct identification of many genotypes.

Research in this field may be relevant for studying mechanisms of cancer induction and for increasing the sensitivity of studies aimed at identifying human carcinogens. This makes research in this field particularly important. In contrast, prediction of future cancer risk in exposed workers is far from offering reliable perspectives, and it is unlikely that its relevance will change in the near future. Also, the wide variation among individuals in their responses to toxic substances, is determined only in part by genetic factors.

For identifying known 'gene variants' ('genetic polymorphisms') DNA has to be extracted from human body cells. A two milliliter peripheral blood sample is commonly used for this. It may be used in **pre-employment testing**, as part of practices with a very different social impact, as for instance: (i) to ensure appropriate placement at the workplace ; (ii) to exclude job applicants with increased susceptibility to disease; (iii) to carry out studies with a view to setting limit values that take account of the more susceptible subgroups; and (iv) to provide individual health counselling.

It is worrying but not surprising that genetic screening test results have a very deterministic connotation with respect to individual susceptibility , while such a conclusion is only justified for a very limited number of diseases which have nothing to do with exposure to 'xenobiotics': susceptibility to the effect of xenobiotics is the result of the interaction of many known and unknown genetic and non-genetic (exposure) factors .

Individual susceptibility

Although everyone is more or less susceptible to the adverse health effects of chemical and physical agents, people working under identical conditions may show inter-individual variation in the intensity of the effects of a particular degree of exposure. This is the exposure–effect relationship. Individuals who are said to be 'more vulnerable', 'more sensitive', 'hypersensitive' or 'more susceptible' show a particular effect, such as chromosomal aberrations or asthma after relatively lower levels of exposure to genotoxic agents or to allergens respectively. Furthermore, the effect in one individual can vary over time and with other factors, resulting in intra-individual variation. The exposure–response relationship illustrates the proportions of individuals who exhibit a particular response at a variety of levels of exposure and reflects inter-individual variation in all of the factors involved. In the case of a clear, bimodal dose–response curve (there is no continuum in the degree of effect in a population, but some people clearly show an effect while others don't), it is in principle more likely that a susceptibility factor (or a combination of such factors) could be identified that would make it possible to distinguish people with increased susceptibility from those less susceptible. Thus, although differences in occupationally related individual health risks may be due to differences in exposure to occupational hazards, huge differences may be seen in health impairment (and test results) in workers similarly exposed to the same substance.

The underlying causes of this variability in response between individuals with the same occupational exposure include differences in environmental factors (other past or current occupational and non-occupational exposure), in biological factors (age, sex, previous or current diseases) and factors associated with lifestyle (nutrition, tobacco and alcohol consumption and stress). These can be referred to as 'acquired' susceptibility factors. In addition, as individuals differ in genetic constitution, the variation in response can be influenced by differences in hereditary factors, which may for instance affect the rate of detoxification of substances entering the body (xenobiotic metabolism). These are 'inherited' host factors of susceptibility**. Differences in susceptibility between individuals result from**

a complex interaction between acquired and inherited susceptibility factors, which are different for each individual. Variation in response to a similar occupational exposure situation within one individual may in some cases be explained only by acquired factors. One of the best known examples of interference between lifestyle and occupational exposures is the dramatic difference in lung cancer risk of smoking and non-smoking asbestos workers, due to the apparent multiplicative effect of the combined exposure (smoking and asbestos) on lung cancer risk.

In conclusion, one can say that since individuals differ greatly and since most of the factors which may affect a particular vulnerability are unknown, prediction of future health will - in almost all cases - be to a very large extent unreliable. In contrast to growing opinion, genetic screening as a possible part of pre-employment testing is unlikely in the near future to change this. Genetic monitoring as a possible part of medical surveillance will rather be relevant at a group level, and much less predictive at the level of the individual cancer risk.

Possible relevance of non–genetic and genetic susceptibility testing in preventing occupational disease

Epidemiological research has revealed correlations between some markers of susceptibility and the risk for occupational disease in populations of workers exposed to agents known to be causal factors. These findings have led to reasoning in support of screening for these indicators of susceptibility and subsequent exclusion of the carrier(s), such as (1):

1. A particular exposure is associated with an increased relative risk of a specific work-related disease.
2. A selection test allows the identification of individuals with a relatively higher susceptibility for that disease.
3. Exclusion of individuals identified as more susceptible will protect their health.

A closer analysis of practices, addressing accuracy, relevance, need and consequences, may illustrate why such conclusions - although derived from seemingly rigorous premises - may be misleading.

An example in this respect concerns risk of atopic status for developing asthma when working in a laboratory with rats (annex 2). The example shows that although the correlation of risk for asthma with a positive skin prick test is very significant at a group level, the prediction at the individual level and the reduction of the number of cases of asthma when persons testing positive at a pre-employment examination are excluded, is almost negligible.

It should always be remembered that **even when epidemiological data show a clearly significant relative risk related to a particular susceptibility factor, the relevance of testing for this factor with a view to selecting applicants may be very weak and contestable**. The reasons include

- a limited intrinsic predictive value of a test, with false positives being excluded and false negatives being employed;

- the number of people that would be excluded, which depends on the prevalence of the factor. Also, the lower the prevalence, the weaker the intrinsic predictive value, resulting in more false positives and false negatives;

- the low yield selection may have in comparison with other ways to control risk;

- the reductionistic concept of a selection approach, confusing (total) health status with one single factor or disease;

- the limited outcome predictive value or relevance of a test in predicting the risk for disease.

Medical relevance of testing practices is based on the assumption that a test will indicate the extent to which a person is more likely to develop the disease if exposure continues than with no exposure, all other variables being equal. But the other variables do not remain equal in reality.

In susceptibility testing for individual risk for disease, the 'outcome predictive value' of a test should not be confused with the preventive action needed to protect an individual's health. In pre-employment testing, for example, the career of an employee might be jeopardised if he or she were identified in a susceptibility test as being at increased risk for disease and therefore denied the job. The relative risk assumed to be associated with a positive result is usually extrapolated from the results of studies in specific populations with specific situations of duration and intensity of exposure. However, the tested person might be exposed for only a few months, as the first step in a long career in other departments of the same company. In this case, the risk for disease associated with unemployment might be a greater threat than working for a few months in the risky work place. The relevance of a series of pre-employment testing practices for an individual may differ with future exposures and dose variables, and the outcome predictive value of a susceptibility test may vary with duration of exposure.

The same is true for susceptibility factors and level of exposure: the differences in relative risk between people with positive and negative results in tests for susceptibility may change as the level of exposure increases(2). The duration and level of future exposures must therefore be taken into account in assessing the relative risk for an individual correctly. Furthermore, not all of the susceptibility factors involved are well understood. The practice of excluding people without understanding the nature of the correlation between a susceptibility factor and the relative risk for a particular disease would be highly questionable.

Also, the analysis of currently possible genetic polymorphism testing practices has shown that these should not be considered to offer a relevant basis for excluding persons. It is strange and worrying to see how the perception of –current or future- genetic testing and the interpretation of genetic test results seem to be coloured by deterministic thinking. The correlations found through epidemiological research between some genetic susceptibility factors and a particular risk for occupational disease should not be interpreted in a deterministic way or used in a reductionistic way. This would be an error of thought, confusing correlation with predictive value; an error in defining the aims, confusing protection against one particular disease with total health protection, and an error of approach, assuming that occupational health problems can simply be solved by selection. Such errors of concept may lead to misclassification of applicants with respect to fitness for the job and protection of their health. One could say that the most important cause of misclassification is misconception and that such a reductionistic and predictive concept may easily result in adverse consequences for the health and well being of individuals.

In contrast to growing belief, reductionistic and deterministic thinking is likely to be even more erroneous in relation to genetic susceptibility testing than in relation to traditional (non-genetic) testing.

These considerations on relevance of a practice illustrate how both relevant or irrelevant decisions could be made based upon test results, depending on correct or incorrect perception. This demonstrates the need for professionalism in interpreting test results. As relative risk is just that 'relative', the proper use of a testing practice depends on a correct understanding of the elements that

[2] It is often assumed that the higher the level of exposure, the more useful it is to select out highly susceptible workers. This was the reasoning, for instance, in the Nuffield Report. But this is probably not always the case as was illustrated by the study of Nakachi on oat cell carcinoma of the lung, genetic susceptibility and level of exposure in Japanese and also by a study of Paolo Vineis on the relationship between ABP Hgb-adducts and urinary nicotine and cotinine in slow and fast acetylators respectively: it might be at low levels of exposure that the difference in susceptibility results in differences in disease or adverse effect outcome, since as the level of exposure increases, the difference in risk between susceptible and non-susceptible people tends to decrease.

contribute to the relativity of risk in relation to a personal risk factor, and on an awareness of any lack of knowledge in this respect. Dealing with these scientific uncertainties requires a high degree of professionalism.

Profession, professionalism, relevance of genetic and other medical testing and objectives in occupational health.

Although several professional disciplines can and should contribute to the prevention of adverse health effects, data regarding collective and individual health risk in relation to working conditions must be interpreted by medical professionals trained in occupational health. They should have the expertise required to interpret susceptibility and surveillance test results within the wider context of total health protection, taking into account not only the job requirements and the working conditions but also the possibilities for further measures of primary prevention and/or medical surveillance in order to anticipate possible health problems. This professionalism enables occupational health physicians –in close collaboration with other occupational health professionals- to maximise the likelihood of identifying workplace health risks, to advise employers and other collaborators of preventive services on improving workplaces and adapting tasks, to advise individuals correctly on optimal job placement and to limit exclusion for health reasons to as great an extent as possible. Professional competence and a clear, legal definition of the role of the occupational health practitioner in protecting the health, work and privacy of workers could constitute a solid basis for inspiring the necessary trust and confidence in workers. This in turn may provide the occupational health professional with better information about the workplace situation and how individual workers and the workforce can be better served.

The absence of this professionalism and of an organisational framework which enables it to fulfil such an unambiguous role will almost inevitably result in a more reductionistic, over-simplified or incomplete approach to health evaluation and health protection which puts too much emphasis on single test results. This may easily lead to the unjustifiable exclusion of persons and also to putting some individuals at risk erroneously. This may be the case in what we have been modelling as a standardisation approach.

Anchoring a health and employment protection approach in pre-employment medical practices.

If a genetic testing practice proved relevant in identifying a person at considerably increased risk for a severe disease in relation to a particular occupational risk, and which is not preventable by other means, would it be a medical mistake not to use the test? The use of relevant genome testing practices and the possible consequence that a job would be denied to a candidate does not 'in se' constitute a major threat to a 'social justice' (health and employment protection) approach in occupational health practice. The context of pre-employment examinations may do so. A series of rules are proposed which –if respected- could prevent irrational use or misuse otherwise in pre-employment testing practices:

- only medical doctors with special training in occupational health and who are familiar with the future working conditions of the applicant should do pre-employment examinations, with the aim of assessing fitness for job and future job related health risk. They shall base their advice on a total health approach and if possible and needed they shall propose that the working conditions be adapted to the abilities of the candidate;
- any other medical examination either done by other physicians or related to other objectives like additional health insurance previous to employment should be prohibited[3];
- a pre-employment examination should be the last step in the procedure to hire a person. This implies that if a person who was sent to pre-employment examination is not hired, it must be assumed that this can only be for medical reasons;
- in that case, the occupational health physician should deliver a written statement to a physician choosen by the applicant in which the reasons for denying a job to the applicant are explained. The content of the document may constitute the basis for an appeal procedure;

Such conditions may considerably contribute to pre-employment medical examinations both being based on scientific rationale and being protective of health and employment of individual job applicants. Obviously, such regulations may especially contribute to controlling other questionable pre-employment

[3] Testing for employment related supplementary health and other insurance is becoming more common, especially in larger companies. When done at the pre-employment examination, this may lead to those persons considered to be at increased health risk being refused a job for reasons that are not related to workplace health risk. The only possible solution is likely to be the prohibition of insurance related testing in a pre-employment context. Moreover, insurance companies should never have access to information on the genetic constitution of workers or genetic biomonitoring data, or to any other medical information generated in an occupational health context, as the purpose of such information must be to prevent disease, and not to predict disease for the purpose of exclusion.

testing practices such as HIV seropositivity testing, which is not uncommon despite the fact that its relevance for occupational health protection is limited to extremely exceptional situations.

Because assessing the relevance of genome screening is extremely difficult and its application a sensitive issue, and also since genome screening tests will probably be subject to the commercial interests of companies marketing these tests as simple test kits, prohibition of genome testing practices at pre-employment examination should be the general rule, and be part of the law. Exceptions to this rule should be allowed only by the highest national democratic authority following thorough scientific evaluation resulting in clear indications of the relevance of a particular testing practice in well defined exposure situations. In that case (which is likely to be rare), undergoing testing should logically be a pre-condition of getting the job.

Decisional autonomy of the job applicant or employee which is embodied by the principle of individual informed consent should not be a substitute for proper regulations in the field of medical testing practices in the workplace, especially at pre-employment examinations. There are several reasons for this: the accuracy of the information provided may be limited (it is unclear how the complex relationship of genetic polymorphisms, exposure and disease risk may be clarified to individual job applicants); the authenticity of the consent may be questionnable (i.e. because the perceived power inequality between provider and receiver of information, especially in a pre-employment context); and the decision of the individual may conflict with the interest of others or with other interests. For instance, the freedom of the individual employee to decide for oneself may form a discordant pair with the need for risk reduction resulting in the obligation for the employers to reduce risk: their full co-existence is illogical and likely to result in drifting away from a health and employment protection approach. Adherence to the principle of an individual's right to decide and thus applying the principle of informed consent to a test or to working under risky conditions seems to be a rather consistent part of the discourse in favour of a standardisation approach.

In occupational health, tripartite negociations at national level (social partners and public authorities) with expert participation is the most common way to develop laws and regulations both at EU level and in Members States. When negociating on the role of occupational health professionals, trade unions implicitely are giving a collective dimension to the informed consent principle. Trade unions are considered as mandated by their members. This may be helpful in avoiding possible conflicts between the individual's right to decide and the interest of third parties, such as other employees., Traditionally, trade unions were above all concerned with improving the working conditions and work related health surveillance of employees. Rather little attention was given to the rights of job applicants.

However, a democratic and socially oriented society must not tolerate pre-employment related practices which are not in compliance with moral values in society at large. Such practices may considerably affect societal perception of "normal", "healthy" and "able" and lead to unjustified discrimination against individuals. Since decisions in the field of occupational health may affect moral values in society at large, and since agreements between social partners are not always unequivocally to the benefit of job applicants, of the work force in general, and of society as a whole, parliaments should have a key role in the decision making process in so far as needed to guarantee that legal requirements and practices comply with the principles of respect for human dignity and social justice.

Conclusion:

Occupational health policies should comply fully with the institutional beliefs of the democratic, tolerant and socially oriented societies –which is usually the case in European Union Member States- in which they are embedded. A de facto socio-ethical balancing of values other than those governing society as a whole in the context of labour and industrial relationships - for instance in pre-employment testing - may cause a shift in prevailing moral standards. Depending upon their use, new technologies may affect these moral standards, not necessarily because they highlight new problems or new thinking, but because they may magnify them and therefore affect moral reality in society. This is why there should be societal awareness of issues such as the use of genetic techniques in occupational health settings. **Definitions of 'normal', 'healthy' and 'able' and the way in which scientific uncertainty is dealt with may shift as new genetic screening techniques are applied**. Irrational use of genetic testing may be stimulated by the interest of companies marketing such tests on the one hand and by the prejudice that prediction of future health is possible and that it should be part of good managerial practice on the other. Parliaments must create the necessary legal conditions to prevent unjustifiable discrimination against individuals for health reasons in pre-employment situations. **Four rules are proposed in the text which together may lead to anchoring a health and employment protection approach in pre-employment testing**. The context of genetic and other testing practices is the key issue with regard to their possible scientific relevance, and their possible use should only be considered if the conditions are created to use these to the benefit of workers' health. In so doing, an irrational and discriminatory use of genetic testing and other testing practices may be prevented. Current scientific knowledge on genetic polymorphisms in relation to occupational health risks makes it rather unlikely that genetic screening testing practices may be relevant in preventing occupational health problems.

Annex 1

In a **health and employment protection approach to occupational health**, in addition to general preventive measures which should make jobs accessible to more (potential) workers without known risk for adverse health effects, pre-employment medical examinations and preventive measures at the workplace are used as complements to protect the worker, giving him or her a job that corresponds to his or her fitness and if necessary adapting the working conditions to the abilities of the individual applicant. Medical surveillance and preventive measures at the workplace are also used as inseparable complementary instruments by the occupational health physician with a view to both allowing employment and protecting health. Medical surveillance is used to check compliance of the (changing) working conditions with the (changing) abilities of the worker, to control for any indication of an adverse health effect at the earliest possible stage and to monitor absorbed doses in groups of workers as part of surveillance of the environment. Such a preventive approach is oriented towards all workers and potential (including currently not employed and unemployed) workers collectively and to every individual worker (including for instance chronically diseased or disabled), and is in accordance with the above mentioned socio-ethical values.

In **a 'standardisation approach' to occupational health**, absolute priority is given to the standardisation of machinery, working equipment and protective devices, also using certification procedures. Adaptation and improvement of workplaces becomes synonymous with compliance with a set of standards, including exposure limit values. Compliance with these standards or limits is considered as a guarantee for adequate protection. Such a standardisation approach is presented as a primary preventive and highly protective approach of health at work but implies in reality an extremely reductionistic view of workers'health as it refers implicitly to the model of a – virtual - 'standardised worker'. Workers who do not fit this standard may be less well protected. Pre-employment medical examinations in such an approach will rather seek to assess compliance of the individual job applicants with the standard and will inevitably have to opt for selecting out those who are (supposed to be) more susceptible. Also periodical health surveillance in such an approach may be very reductionistic, focusing for instance on biological limit values as straightforward indicators for fitness or unfitness. Since individuals differ greatly, a health protection policy relying solely on the standardisation of working conditions and working equipment might in reality lead to the exclusion of more workers, for instance on the ground that their health status or biometric parameters do not fit the standard. Such an approach is more likely to reinforce the inequality of nature. It is rather in compliance with a managerial request for

the (assumed) measurability and predictability in financial terms of all issues directly or indirectly related to economical activity including occupational health. Reducing absenteeism and increasing productivity are believed (even if not proven) to be addressed properly by such an approach.

The tools, which are used in a standardisation approach (for instance exposure limit values, certification of machinery, biological limit values, etc…), may also be part of a preventive approach. However, a standardisation approach as modelled here is reductionistic with respect to the concept of health (possibly even resulting in different choices of testing practices) and the concept of fitness for job. Rather than making working conditions more acceptable to every potential worker, it might result in making the working conditions more comfortable for the fittest only. It is presented and might be perceived as being preventive, while in fact its objectives are not only different but also even contradictory to this. Since the dynamics of a standardisation approach is not to strive to protect every worker's health and employment and since it is likely to find its complement in a predictive use of tests leading to exclusion, it may be contradictory to the values of concern.

Annex 2:

In an example adapted from De Kort by Casteleyn, it is assumed that pre-employment screening is to be done before hiring a technician for an animal laboratory and that atopic people are to be excluded from this job because of excess risk of allergic asthma. In order to identify the atopic people among the applicants, a test will be used that has sensitivity and a specificity of 90% under optimal conditions, i.e. that will identify 90% of the atopic people correctly and 90% of the non-atopic people correctly. Assume also that 5% of the job applicants are actually atopic (Table 2). Of a total of 1000 persons, therefore, 50 are really atopic and have an excess risk for health problems after exposure to laboratory animals; however, when these 1000 persons are tested, only 90% of the 50 true positives, 45 persons, will correctly be identified as atopic, and only 90% of the 950 non-atopic people, 855 persons, will be identified correctly as non-atopic. Thus, five atopic people will incorrectly be identified as non-atopic and 95 non-atopic persons will incorrectly be identified as atopic. The predictive value of this test is 32 % as in a population of 1000 persons, 140 persons will be identified as atopic, although only 45 are truly atopic.

How many cases of occupational disease would be avoided by selecting out these so-called atopic people? In theory, selecting out sensitive persons can reduce the frequency of work-related disorders maximally by the proportion that can be attributed to the risk factor under consideration. Assuming that atopic people run a three-fold risk of developing asthma when exposed (to laboratory animals) in comparison with people who are considered normal in this respect and taking into account the sensitivity and specificity of the testmethod used, it can easily be calculated that selection on the basis of atopy may reduce the number of work related asthma cases by a maximum of 8 %4. The cumulative incidence of allergy to laboratory animals in some investigations is about 100 per 1000 technicians. By means of selection, 8 % of the cases (0.8 cases/100) are avoided. In order to find 1000 workers who do not have positive results for atopy, 116 (100 x 1000/860) job applicants will have to be examined, and 16 applicants will be selected out, 11 of them on the basis of a false-positive result.

[4] If for example 10/100 (or 9.5/95) persons in a non atopic population were to develop asthma when exposed to laboratory animals, then in an atopic population 30/100 (or 1.5/5) would become asthmatic when the RR is assumed to be 3. Even though the 5% of atopic people have been selected out, therefore, there will be 10 cases of allergy to laboratory animals among 100 workers; without selection, there would be 9.5 + 1.5 = 11 cases. Selection on the basis of atopy will thus reduce the number of work-related allergies by a maximum of 9.1% (100:11). When the sensitivity of the test is only 90%, the yield will be 10% lower: there will be 10.114 cases in the selected population (9.94 among the truly non-atopic people and 0.17 among the falsely non-atopic), for a reduction of 8.03%, which is less than 1 out of 10 cases.

Under the specific premises used in this example—sensitivity and specificity, 90%; true prevalence of atopic people in the population, 5%; incidence of the disease in the unselected population, 10%; relative risk, 3—for each case of allergy avoided, 142 medical examinations would have to be performed and 20 applicants would be rejected, of whom 14 would be incorrectly diagnosed as atopic and thus wrongly considered as being at excess risk in the case of employment.

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Genetic testing in the workplace: ethical and philosophical perspectives

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Abstract

Surveys in different European countries have revealed public suspicion of workplace screening by employers. Screening is seen as a threat to those tested rather than a ben efit . Since the public have little direct experience of workplace testing in Europe it could be argued that their concerns will be allayed by more information on the state of medical genetics and screening technology. However, while the technology itself must be considered, the social and political context in which the technology will be used is also relevant. For example a screening programme might single out a group which is historically disadvantaged in that society and so contribute to its continuing low status. Screening programmes are usually justified in terms of their consequences, that is weighing up the benefit and harm likely to accrue to individuals and the community in the particular context in which it is to take place. Ethical principles which are considered include autonomy, the prevention or reduction of suffering, the right to a safe working environment, privacy and confidentiality of medical information, fairness and equality of opportunity. The imbalance of power between employer and employee makes it difficult to ensure that the individual is giving voluntary consent or is able to exercise the right not to know about his/her genetic make-up. While it would not be in anyone's best interests to ban the use of genetic test results for employment purposes completely there is a need for safeguards which balance the interests of all parties.

Introducing the Journal of Medical Screening the editor reiterated the principle that 'medical screening is intended to benefit the individuals being screened' (Wald, 1994, p.1). He went on to suggest that another term should be used for mass testing that poses a threat to those tested - like pre-employment screening, 'the implicit policing function is contrary to the concept of screening'. Behind the concern about workplace screening is the acknowledgement that there is the potential for unfair discrimination against employees and some evidence of actual discrimination from the US (Congress of the US Office of Technology Assessment, 1990). What is certain is that tests for more genetic disorders will become available and that the DNA chip will facilitate screening for a whole range of genetic traits (Council on Ethical and Judicial Affairs, AMA, 1998).[1] This paper considers the ethics of employer-led screening beginning with a consideration of the consequences for all parties and then discussing the ethical principles involved. The central question is whether the needs and interests of those screened, their families and communities can be reconciled with the needs and interests of employers. Workplace

[1] In a survey of over 1600 employers carried out by the Health and Safety Executive in the UK, 1 in 3 employers carried out pre-employment health assessments (HGAC, 1999, para.3.6.)

screening encompasses pre-employment screening, genetic monitoring and genetic screening for traits not normally classed as occupational diseases. [2]

Benefits and risks

I want to start by considering the ethics of all types of workplace screening from a consequentialist perspective, weighing up the benefits and risks to all parties. At the recruitment stage employers screen prospective employees for genetic information which may reveal that working conditions would damage their health. This might seem beneficial to all concerned. Excluding workers at risk would reduce costs and increase efficiency for the employer. Benefits for individuals could include their health and well-being and the prevention or reduction of suffering. The employer could reduce costs and increase the efficiency of the workforce. Screening should benefit the community by reducing occupational disease, thereby reducing health care costs. It could also contribute to public safety by excluding those with disorders from particular jobs in which their symptoms might endanger the public.

The impetus for screening has come from the employer, does this make pre-employment screening ethically different from screening within a health service? Within the health service genetic screening has been primarily intended to benefit the person being screened. The information may improve the person's health through treatment or allow them or family members to make informed reproductive choices and life style decisions. Even where screening programmes have been introduced in European countries with the aim of reducing the incidence of affected births the individual can usually decline screening without their health care or economic position being affected. Employer screening introduces another party into the procedure, one whose interests are not necessarily the same as that of the individual/family or society. As a consequence of the information obtained individuals may be excluded from a particular kind of job for which they were qualified, with economic and psychological effects both for them and their families and the violation of their right not to know (Hoedemaekers, 1999, p.112).

2 The term genetic screening rather than testing is used throughout the paper. The term screening is normally reserved for a population programme where there is no previous suspicion that the individuals have the particular condition. Some workplace tests might be defined as genetic testing rather than screening because there is some reason to think the individuals are at risk.

Quality control and interpretation of results

There is concern over the management of screening programmes including the way the programme is presented to the employees and job applicants, the quality of the tests, storage of personal medical information and access to this information. Should there be pre-test and post-test information and counselling, and, if so, would those giving it be paid by the employer? Previous research has shown that it is possible to alter take-up rates for genetic tests simply by the way a test is offered (Clarke, 1997; Bekker et al, 1993). Will the usual value put on unbiased information and on confidentiality of medical records be maintained where screening is organised and controlled by an employer?

If the working conditions pose a danger to someone because of their genetic make-up does this justify the screening programme to identify them? The problem with weighing up costs and benefits in this way is that there are uncertainties and dangers in genetic information. To begin with, no test is 100 per cent accurate. There will be a percentage of false negatives and false positives. For the employer it may be most important that a test is highly sensitive, so that it detects a high proportion of those who have the disorder. However, a test with high sensitivity will also tend to have a high proportion of false positives. While the employer with access to a large pool of labour can simply employ someone else, the individual concerned has been given false medical information and excluded from employment. Where the test result is accurate it is unlikely that the risk of developing the disorder is 100 per cent and if the disorder does develop there is the question of the degree of suffering which will be associated with it. Should the worst case scenario always be considered? If an increased risk is identified how should this be interpreted? People take risks to their health and safety for all sorts of reasons in everyday life and leisure activities. The risk information given by a test result has to be seen in the context of the person's life as a whole.

Screening for susceptibility to multifactorial disorders

It might appear that the numbers of workers at increased risk of developing a genetic condition because of their working environment would be small. However, if the range of features to be considered is extended from chemical or biological agents then far more could be affected. It could be more economic to exclude a wider group of people at risk of future ill health rather than provide facilities for some of them at a later date. Screening for susceptibility to multifactorial disorders could be part of the

recruitment process, used when selecting employees for promotion or as a health promotion service for existing employees coupled with education on smoking, diet and exercise. Whether the information serves to promote health or to stigmatise a group of currently healthy people depends on the way it is used.

For example, individuals with susceptibility genes for mental disorders might be more vulnerable than other workers to stress or isolation (Nuffield Council on Bioethics, 1998 p.59). The Nuffield Council report on mental disorders and genetics stated that 'employers might use...information [from genetic tests] to ensure a healthier work force with lower sickness rates; pension funds might use it to reduce the costs of early retirements. Policies of these sorts could have serious adverse implications for people whose genetic test results indicate a susceptibility to mental health difficulties' (ibid). Workers identified as genetically susceptible to a disorder would not necessarily be covered by anti-discrimination legislation designed to protect those with disabilities since the disability is potential rather than already present. Those with mental health disorders are already subjected to stigma and discrimination and find it difficult to obtain employment unless they can conceal their psychiatric history (ibid, p.58). Pre-employment screening for susceptibility genes for any multifactorial disorders would have adverse effects on individuals by excluding them from employment and restricting their type of employment or access to benefits, as well as causing concerns about their future. While the genetic component is self-evidently only one factor in a multifactorial disorder, genetic information tends to be seen as particularly accurate and determining (Nelkin and Lindee, 1995). Individuals receiving the 'genetic warning' are not necessarily empowered by it since if and when problems show up they will be personally responsible in a different way than if there had been no genetic forewarning. The changes in lifestyle and other measures to try to reduce the risk may not be feasible for economic or social reasons.

In general the working conditions that would be suitable for someone with sensitivity to a chemical or biological agent in the workplace would benefit all workers, that is, the provision of protective equipment and minimum exposure to hazards. Similarly, it is not only workers with susceptibility genes for a mental disorder or cardiovascular disease who would be affected by work which offered an excess of stress, danger, isolation and a lack of opportunity for physical exercise. These conditions do not benefit anyone's health. The principle of health and safety at work legislation is that removal of the worker from employment is the last resort. The aim should always be to try to remove the risk (Health and Safety at

Work Act, 1974). The Nuffield Council recommended that employer led screening "should only be contemplated where ...the condition is one for which the dangers cannot be eliminated or significantly reduced by reasonable measures taken by the employer to modify or respond to the environmental risks" (Nuffield Council, 1993; HGAC, 1999). It is conceivable that testing might be undertaken by employers to exclude those with multifactorial conditions which present risk factors for future health, but are not related to the working environment (as has happened in the US where employers cover workers for health care costs, Geller et al, 1996).

Ethical principles

In assessing the risks and benefits of employer-led screening in Europe the ethical principles are seen to be autonomy, informed consent, the right to know and the right not to know, the duty to help, the duty to avoid harm and equity (Chadwick et al, 1998).

Autonomy and informed consent

The principle of autonomy 'demands fundamentally that adults of normal competence are respected as responsible decision makers in matters pertaining to themselves' (Husted, 1997, p.57). Genetic information may enhance autonomy where it enables a person to make important life choices which will maximise well-being. The process of genetic counselling, which has been part and parcel of genetic screening programmes, is based on the principle of autonomy and requires the individual freely to give informed consent before a test is carried out. The individual must therefore be given the necessary information and counselling before being asked to consent to a test. However, in pre-employment or workplace screening it is difficult to say that the worker has consented freely to the procedure. If the test is offered by an employer to job applicants it may be refused, but, if the consequence is the loss of a job offer then there is indirect coercion rather than any real choice. To exercise autonomy people need the opportunity and resources to make choices and be in control of their lives. Within the employer-employee relationship it is difficult to ensure that the individual is giving voluntary consent or is able to exercise the right not to know about his/her genetic make-up. There are some instances where it is clear that a worker will develop a disorder, which seriously endangers health, due to a feature of the workplace environment. In these cases it may be argued that there should be limits to the exercise of

individual autonomy from a public health or communitarian perspective. Similarly, public safety requirements might demand limits to autonomy in specific jobs.

Employees may, of course, welcome screening because they see benefits from having good test results. There is a tendency for members of the public to be enthusiastic about screening but this may be because they assume that they will be free from any genetic disorder. When the Gene Shop was set up in the UK, as a public education facility funded under Biomed 2, a survey of visitors and staff asked for opinions on genetic testing for themselves, partners and children, including testing where no treatment was available. The staff, who were either medical doctors or health visitors specialising in genetics, were less enthusiastic about all types of testing than were the visitors. The most enthusiastic were those who had not actually come into the Gene Shop at all but were passers-by (Levitt, 1998, p.23). This indicates that enthusiasm for genetic testing should not necessarily be taken at face value since the enthusiasm may wane once people have more knowledge of the consequences. Just as mothers have prenatal testing 'to make sure the baby is all right', employees might anticipate reassurance of genetic health rather than 'bad news' (Lippman, 1991)..

The right to know and the right not to know

The model of the autonomous individual making informed choices is not only problematic because of the particular situation of being an employee (or prospective employee), there is also the fact that genetic information has implications for other family members. The decision by one person to be screened may lead to the unsolicited disclosure of genetic information to relatives with the loss of their 'genetic innocence' and hence their right *not* to know (Chadwick, Levitt and Shickle, 1997). Information on one family member could affect the employability of other relatives (e.g. if one person tests positive for a late-onset genetic disorder or for a multifactorial disorder).

Privacy

Respecting a person's privacy may respect or enhance their autonomy but the right to privacy often conflicts with stronger claims of society (McGleenan, 1997, p.48). 'Individuals already forgo significant levels of privacy in order to obtain the social goods that benefit society collectively' (ibid). For example,

medical information is held on computer systems. It is where the revealing of information may be to the detriment of the individual that there is concern over its collection and storage. Concern over the privacy of genetic information obtained by an employer comes when it is assumed that the interests of the employer and the employee do not coincide.

The duty to help and the duty to avoid harm

Screening has the potential to help and to harm but so does a failure to screen. The worker who is screened may receive useful health information and be able to take action to safeguard or even improve health. On the other hand, a worker may be harmed by increased anxiety, discrimination and stigmatisation without being able to take effective action to remove the threat to health. The harm caused by a failure to screen and the harm caused by implementing the screening programme should both be considered before the programme is begun (Chadwick et al, 1998).

Equity

The principle of equity or fairness is violated by discrimination based on genetic factors. The individual suffers discrimination in employment because of something for which he or she is not responsible. This distinguishes pre-employment genetic screening from screening for drug or alcohol abuse (although these may have a genetic component). Moreover, the discrimination may single out particular ethnic groups who are already disadvantaged and stigmatised leading to serious social consequences. There is potential for the abuse of genetic knowledge by employers whose focus is the competitiveness of their own workforce rather than the wider social effects of their policies. For employees who test negatively the question is whether they should be able to use their genetic good luck to advantage by, for example, adding the results to a curriculum vitae.

Conclusion and implications for policy

The ethical questions raised by genetic screening are often met with scientific information which directs the debate to the genetic technology itself and away from the social and political context in which genetic technology will be used. However, the context of screening is particularly important where there is an imbalance of power, such as that between employer and employee, or prospective employee.

It is not in anyone's best interests to ban the use of genetic test results for employment purposes completely, for example, where the working environment poses a specific risk to those with certain genetic traits or affects their ability to perform a job safely. However, it is conceivable that a widening of the scope of genetic screening, both pre-employment and for existing employees, could be attractive to employers but incur individual and social costs. The need for a cautious approach is indicated, one which relates screening to particular jobs.

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The legal aspects of occupational health

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1. INTRODUCTION

Initiated by the human genome project, health status - and particularly any predisposition to disease - is becoming increasingly detectable. As tests become simpler to administer and their use expand, a growing number of individuals may be labelled on the basis of (predictive) genetic information - "The healthy ill" - thus facing the risk of feeling discriminated against. Anticipated discrimination has been debated to such an extent that the term "genetic discrimination" has been coined to denote this.

Health information - especially the use of genetic testing - may violate *privacy*:[1]

* Genetic data may offer information *unknown* by the tested subject;

* Genetic data may disclose a genetic disorder of *future uncertain* importance;

* Genetic data may offer information about progeny and other relatives;

* Genetic data may permit a *permanent classification* of the tested subject and his/her relatives in one or more "risk categories" of the population.

Privacy is related both to protection of the person's *inner sphere* - the right to *autonomy* and informational self-determination- and to the relationship between a person and the *surroundings*, especially the public sphere - the right to have a "*private space*". The key principles seem to be the "right not to know" one's own hitherto unknown secrets incl. that of being a healthy ill, and the right not to have others to know about health status, including genetic traits. These rights are fundamental and are put into much sharper focus by the psychologically straining effects from predictive genetic information.

In the field of employment the prospect of using health information incl. genetic screening detecting both occupational and non-occupational-related traits is in the international debate seen as realistic in the workplace hiring practises. This is seen as quite alarming in that it may introduce a new form of discrimination leading to a new class of "unemployable" persons.

[1] A comparative analysis of the legal situation in Denmark compared to Italy has been made by Linda Nielsen, Denmark, and Stefano Nespor, Italy, in an EU-funded project: "GeneticTests, Screening and Use of Genetic Data by Public Authorities in Criminal Justice Social Security, Health Care and Alien and Foreigners Acts". The report has been published by the Danish Centre for Human Rights, 1994.

2. CONVENTION AND LEGISLATION

The Council of Europe has addressed the topic in the Bioethics Convention from 1996 (Convention on Human Rights and Biomedicine)[2], where the non-dicrimination principle has been stated in article 11:

"Any form of discrimination against a person on ground of his or her genetic heritage is prohibited".

Moreover, predictice genetic tests has been restricted to certain purposes in article 12:

"Tests which are predictive of genetic diseases or which serve either to identify the subject as a carrier of a gene responsible for a disease or to detect a genetic predisposition or susceptibility to a disease may be perfomed only for health purposes or for scientific research linked to health purposes, and subject to appropriate genetic councelling".

In the explanatory report it is expressly stated, that there is an apparent risk that use is made of genetic testing possibilities outside health care (for instance in the case of medical examination prior to an employment or insurance contract) and that the aim is to distinguish clearly between health care purposes for the benefit of the individual on the one hand and third parties´ interests, which may be commercial, on the other hand. Article 12 therefore prohibits the carrying out of predictive tests for reasons other than health or health-related research, even with the assent of the person concerned. National law may allow for the performance of a test predictive of a genetic disease outside the health field in some cases under the condition provided for in article 26. The conditions are a.o. that exceptions are prescribed by law and are necessary in a democratic society in the interest of public safety, for the prevention of crime, for the protection of public health or for the protection of the rights and freedoms of others.

In Europe legislative action has been taken in a number of countries. An example is Norway where the legislation contains special provisions about genetic testing, saying that these are only to be used for medical purposes with diagnostic goals and/or a view to treatment of diseases. The Act bans asking for, receiving, possessing, or using information about another person, which has been revealed due to genetic tests, and also prohibits asking if genetic tests have been carried out.

[2] Convention for the protection of Human Rights and Dignity of the Human being with regard to the Application of Biology and Medicine. Convention on Human Rights and Biomedicine. (Council of Europe Directorate of Legal Affairs. Strasbourg, November 1996). The Convention is supplemented by an Explanatory Report from January 1997.

3. THE DANISH ACT ON THE USE OF HEALTH INFORMATION ON THE WORKPLACE

3.1. Background

In Denmark the employers normally have a discretionary right to appoint people for all kinds of reasons. The private labour market is mainly regulated by the managerial prerogative. In the public labour market the employer has to follow the general principles on public administration, including objectivity and relevance. Before taking the job the prospective employee has a duty to inform the employer about matters of importance for the appointment incl. relevant information about diseases. [3] Under the ethical rules of the Danish Medical Association, members may not issue declarations of health to be used by an employer in assessing applicants, unless so ordered through legislation, or unless indicated by reasons in the patient's favour.

Before 1991, a parliamentary resolution was adopted, by which the Government was directed to present a bill banning genetic testing in connection with employment and insurance. This was based on the genetic possibilities and especially the prospect that within a some one would be able to obtain and use cheap genetic testing for instance as a condition of employment.

The Minister of Labour in 1992 put forward a bill prohibiting the use of genetic tests in connection with employments, pensions and insurance. The bill (No. L 44) was concentrated upon genetic tests that may show whether it is likely that a person will develop a specific disease, and whether the person is in possession of certain genetic characters. The purpose of the bill was to protect the integrity of the individual, to hinder further segregation and selection at the labour market and to protect people from discrimination on genetic grounds. To fulfil this purpose the bill denied the employer the right to ask for or to use any type of genetic test when hiring workers or later. The prohibition was not entirely exclusive

Before 1993, the Parliamentary Labour Market Committee arranged a hearing regarding the bill. A number of specialists took part in the hearing as well as representatives from the labour market. There was a broad consensus that specific regulation of DNA tests apart from other health information seems inadequate, as other similar methods may lead to the same results. Information regarding a genetic test is not easily distinguished from information about hereditary conditions in general, which again cannot easily be distinguished from other sources of health information. Most of the participating panel found

[3] Similarly insurance companies and pension funds are free to ask for any type of medical information. Consent from the person involved is necessary. When obtaining an insurance, the insured is obliged to give correct information.

that there was a need of legislation in the area and a need of quality assurance when the gene technology is used.

The hearing led to the setting-down of a new Law Reform Commission regarding genetic testing in the workplace (of which I was a member). The Commission was set down in July 1993 by the Minister of Labour and completed its work in April 1994.[4] In the report a majority of the Commission has suggested that a ban should embrace not only genetic tests but health information in general in relation to work - and a number of exceptions should be accepted. This was primarily based on the critics directed towards the former bill regulating the method instead of the purpose of using health information.

Based on the report from the Law Reform Commission, a Bill on the use of health information on the labour market was introduced to Parliament in April 1995.
When presenting the Bill the Minister of Labour stressed that the area contains major ethical problems which it is very essentiel to bring forward in a public debate. In Parliament the debate about the Bill was controversial. For some opponents, incl. employers organizations it is seen as an exaggeration to make legislation before problems have been documented. Moreover, it is seen as problematic to introduce rules where it may be difficult to distinguish between information, the employer is entitled to obtain from information the employer is no longer entitled to ask for.

3.2. The Act of April 1996

The Act provides guidelines for collection, taking and use of health information in the workplace. The aim is to protect privacy and integrity of the individual person without hindering the beneficial effects of modern technology. A main purpose has also been to secure the quality of the health information The Act is based on the thought that the employee should have the possibility to reject health information which might detect a serious disease.
According to the Act the employer may obtain information about the employees' health in the following cases:

[4] The Law Refom Commission on Genetic Testing in the Workplace (Gentestudvalget) submitted its report in May 1994 (Gentestudvalgets betænkning om helbredsoplysninger på arbejdsmarkedet - Betænkning nr. 1269/1994).

* When the health information is relevant for the ability of the employee to perform the specific work.
* With the approval of the Minister of Labour with the aim of making allowance for essentiel considerations regarding the security and health of consumers and others as to the outer environment or to other societal interests.
* According to agreement with the trade union or after permission from the Minister of Labour with the aim of making allowance for essentiel considerations regarding the running of the firm.
* As a novel offer to the employee if conditions in the working environment makes it reasonable and desirable in relation to the employee himself or others employed.

The employee must on his own initiative inform the employer about health information relevant for the employee's ability to perform the specific work, if he or she is familiar with this information.

The employer is not allowed to collect information about the employees' health:
* When the information is not relevant for the ability of the employee to perform the work.
* When the information to a larger or smaller degree concerns the probability of the employee coming to suffer from diseases in the future.

Health information includes diseases the employee suffers from, has suffered from or has symptoms of. When requesting health information the employer is obliged to point out the diseases or symptoms the employer wishes to obtain information about.

The quality assessment is secured by regulations securing professional contribution in connection with the examination, confidentiality for the persons involved in the examination, and regulations about informed consent. The person performing the examination must secure that the employee has given informed consent, based on information given orally and in writing. This information should include the purpose of the examination, its kind and method, possible risks attached to it, possible consequences for the employee, storing of the results and conditions of passing the information on. Information should include the possibility that the result of the examination may influence the investigated persons life expectancy and self-perception. Finally it is stressed that the person performing the examination must treat this confidentially. The employee is the person who is to receive the result of the examination and

the employer has no possibility of collecting the information from other persons than the employee. This does not, however, free the employee from the obligation to pass on information to the employer in certain situations, see above. When health investigation is perfomed, the employer is obliged to pay the expenses attached to the investigation.

The Act only regulates the employers admission to collect health information. It does not affect whether or not he has the right to perform ability tests, that is examinations, interviews, etc. of any kind with the purpose of stating if the person in question has the necessary abilities to perform the job, and how good the person in question is able compared to other applicants. This is especially emphasized as such physical or psychological tests may be conditional of the hereditary disposition of the person.

The Act does not exclude the right of the employer to carry out ordinary control arrangements towards the employees, for instance investigations of alcohol or narcotic abuse, when these investigations are not for health reasons.

Finally, the Act cannot be used, when health information is collected in accordance with specific legislation.
The limitation of the Act to the workplace is due to the fact that the area of insurance and pension are deemed to lie within the domain of the Minister of Justice and the Minister for Business and Industry. A special Act on this topic has been passed in June 1997 (Act No. 413 of 10-6-1997). According to this legislation pension funds or insurance companies are not - in connection with or after agreement on pension or insurance - allowed to request, collect, receive or use information which may show a person's hereditary status and risk to develop diseases. Nor are they allowed to demand examinations which are necessary to give such information. Exceptions are made regarding information about the person´s present or previous health condition.

4. FUTURE DEVELOPMENT

Health information, including genetic tests as a condition for employment (or insurance) is a matter of controversy. It is decisive if the right to a work and an insurance are considered a social right, an economic right or just a privilege.

If further protection of privacy and non-discrimination is seen as adequate, very different methods may each play a part.

a. Information and education may raise awareness and contribute to protect against (genetic) discrimination. Muitidisciplinary Councils of Ethics may fulfil a task in this respect.
b. Codes of conduct may provide guidelines for the professionals securing that privacy concerns are adequately taken care of. (And secure high scientific standard).
c. Regulation may be necessary in areas like this where informed consent does not necessarily provide sufficient protection, as the situation is not equal for the parties involved. It is not a matter of saying yes to produce health information or not, but a question of getting the chance of obtaining the job (or insurance) or not.
Regulation may have a norm setting function, declaring certain values worth protecting, a.o. discrimination based on health information. This function is based on the vision that law may be educational - a way of implementing ethics. Regulation may also have a protective function, protecting weak groups, a.o. persons with certain predictive health information, against discrimination. Finally regulation may have a regulative or declarative function, securing clarity, enabling the persons involved, a.o. employers and insurers, to know what is accepted/not accepted so they can act accordingly .

5. CONCLUSION

In my opinion legislation banning the collection and use of certain kinds of health information in the workplace is adequate.
This is based on the following:

* That we are (normally) not morally responsible for our health status.
* That information and self-determination should lead to a right to determine scope and degree to which one will reveal personal, health information .
* That the employer is (normally) only entitled to get information about actual diseases relevant for the specific work.
* That extensive health information may result in creating new social categories, excluded from employment.

* That predictive health information is very often uncertain and probabilistic, which may mean that people who stay healthy are discriminated against for no reason.
* That informed consent does not provide sufficient protection as the applicant's desire to get the job renders the consent of little value.
* That it is essentiel to introduce legislation in such areas before the problems arise, as it is preferable that policy considerations do not trail behind the eventof new technologies, but that we become prepared through legislation and regulations to deal with the unintended effects of new kinds of health information.

Annex 1

**Act on the use of health data etc.
on the labour market**

Act No. 286 of 24 April 1996

**Ministry of Labour
Denmark**

Act No. 286 of 24 April 1996

Act on the use of health data, etc. on the labour market

Part I.

Purpose and scope of the Act

1. - (1) The purpose of the Act is to ensure that health data are not used wrongfully to limit the possibilities of employees for obtaining or maintaining employment. This shall apply irrespective of whether the data relate to genetic tests, ordinary examinations or come from any other sources.

(2) The Act shall apply to the use of health data on the labour market. However, the Act shall not apply to the extent that rules on the use of health data have been laid down by special legislation or by provisions issued on the basis of such legislation.

(3) In this Act requests for and collection of health data shall also be taken to mean the carrying out of examinations to the extent that these are required in order to obtain the health data concerned.

Part II.

Collection of data

2. - (1) In connection with recruitment or during the duration of an employment relationship an employer shall only be entitled to request health data to be provided for the purpose of ascertaining whether the employee in suffering from or has suffered from a disease or has or has had symptoms of a disease if the disease will be of significant importance for the employee's capacity for work in the job function concerned, cf., however, sections 3 to 6.

(2) However, the employer may only request information, cf subsection (1), of which the employee is not himself informed, if the conditions in connection with the work concerned specifically justify that such data should be provided.

(3) When requesting data under subsections (1) and (2) the employer shall inform the employee of the diseases or symptoms of diseases on which he seeks information.

(4) An employer shall not - in connection with recruitment or during the duration of an employment relationship - request, collect, receive or make use of health data for the purpose of ascertaining the employee's risk of developing or contracting diseases, cf., however, section -3.

(5) The provisions laid down in subsections (1) to (4) shall also apply to consultants and other persons acting on behalf of the employer.

3. - (1) An employer may offer that health data are collected for the purposes mentioned in section 2 (1) and (4) if working environment conditions make it reasonable and appropriate to do so for considerations of the employee himself or other employees.

(2) Collection of data under subsection (1) shall be instrumental in the prevention of workconditioned diseases or improvements in the working environment conditions. The rules and guidelines laid down in the working environment legislation on examination methods and use of experts shall be correspondingly applicable.

(3) The employer shall notify the local working environment service before such examinations are carried out. The notification shall include detailed information on the examination, including its extent, method, etc. and on the persons assisting in and in charage of the examination. The examination may not take place until 4 weeks after the working environment service has received the notification.

(4) When a health examination takes place the employer shall -
(1) give the person who carries out the examination any necessary information to be used in this connection,
(2) pay the costs in connection with the examination, and
(3) ensure that the examination can take place without any loss of income for the employee and, if possible, during normal working hours.

(5) The Director of the National Working Environment Service may decide that an examination should not be carried out or should be suspended if it does not satisfy the requirements laid down in subsection (2).

(6) An appeal may be brought against the decisions of the Director in accordance with the same rules as those applying to decisions under the Working Environment Act. However, an appeal shall not have suspensive effect in relation to the decision.

4. - (1) The Minister of Labour may - after having obtained the opinion of the Council mentioned in section 8 - permit that an employer arranges for data to be provided on whether the employee is suffering from a disease, has symptoms of a disease or may be infectious, to the extent that this is necessary in the interest of
(1) the safety and health of consumers or other persons,
(2) the external environment, or
(3) other community interests.

(2) It is a condition for requesting health data that the interests concerned outweigh the interests of the employee and that it is not possible for the enterprise to take these interests into consideration in any other way.

(3) Health examinations shall be carried out by using the least radical method which wffl serve the purpose.

(4) Section 3 (4) shall be correspondingly applicable.
5. - (1) An employer may arrange for provision of data on whether the employee is suffering from a disease, has symptoms of a disease or may be infectious when this is considered necessary for considerations of the operation of the enterprise, cf., however, subsection (2).

(2) It is a condition that the employer or the organisation of the employer concludes an agreement about this with the opposite employee organisation(s), cf., however, subsection (3). The agreement shall be sent to the Minister of Labour for the purpose of information.

(3) In those cases where no agreement can be concluded according to subsection (2), the Minister of Labour may - after having obtained the opinion of the Council mentioned in section 8 - give permission to a request for provision of health data.

(4) Section 3 (4) and section 4(2) and (3) shall be correspondingly applicable.

Part III.

The employer's duty of disclosure

6. Before the recruitment the employee shall of his own will or if questioned by the employer inform the employer whether he is cognizant of suffering from a disease or has symptoms of a disease which would be of significant importance for the employee's capacity for work in the job function concerned.

7. If the employer.should - on the basis of the data obtained by virtue of section 4 and section 5 - take special measures in connection with the work or make other dispositions, the employee shall ensure that the employer is informed hereof.

Part IV.

The Council of Experts

8. - (1) The Minister of Labour shall set up a Council which shall submit opinions at the request of the Minister of Labour or on its own initiative in cases which are sent to the Minister in accordance with section 4 (1) and section 5 (2) and (3).

(2) The Minister of Labour shall appoint the chairperson of the Council. In addition to the chairperson, the Council shall be composed of 16 members to be appointed by the Minister of Labour at the recommendation of the following authorities and organisations:

1 representative of the Ministry of Labour,
1 representative of the Working Environment Institute,
1 representative of the Ethical Council,
1 representative of the Directorate of the Working Environment Service,
1 representative of the Ministry of Business and Industry,
1 representative of the Association of General Practitioners,
1 representative of the Ministry of Justice,
1 representative of the National Board of Health,
1 representative of the Central Organisation of Professional Associations,
1 representative of the Federation of Salaried Employees' and Public Servants' Organisations,
1 representative of the Main Organisation of Managers,
1 representative of Federation of Danish Trade Unions,
1 representative of the Danish Employers' Confederation,
1 representative of the Ministry of Finance, the National Organisations of Municipal Authorities and the National Organisation of County Authorities jointly,.
1 representative of the Association of Employers in the Finance Sector,

1 representative of the Association of Employers in Agriculture.

(2) The members shall be appointed for a term of 3 years at a time. They may be reappointed.

(4) The Council shall lay down its own rules of procedure.

Part V.

Informed consent

9. - (1) Before an examination is carried out for the purposes mentioned in section 2 (1) and (4), cf. section 3, the person who carries out the examination shall ensure that the employee has been informed in writing and orally about:
(1) the purpose and nature of the examination,
(2) the examination method,
(3) any risks in connection with the examination,
(4) any consequences which the results of examination may have for the employee,
(5) the nature of the information which may result from the examination, including the degree of the risk of future disease, etc.,
(6) the conditions for passing on data, cf. sections 7 and 11,
(7) follow-up to the examination, including notification of the employer,
(8) how the results of the examination will be stored,
(9) where warranted by the nature of the examination, also the possibility that the result of the examination may have an impact upon the expectations to life and self-opinion of the person examined.

(2) Before the examination is carried out, the employer shall ensure that the employee is informed about any possible consequences which a refusal to undergo the examination may have for the employee.

(3) The examination may only be carried out, if the employee has given his consent in writing. The employee shall be given a time limit of at least 2 working days for giving his consent after having been informed as mentioned in subsection (1).

(4) If an employee expresses a wish for restrictions in the data concerning the evaluation of the consequences which the results of the examination may have for the employee or if the examination will have an impact on the expectations of life and the self-opinion of the person examined, the person who informs the employee about the results and interpretation of the examination under section 10 (4) shall respect such a wish.

Part VI.

Experts

10. - (1) A request for the carrying out of an examination under sections 2, 4 and 5 shall be made by the employee and at the employees own choice either to the general practitioner normally used by the employee concerned or to a similar expert in the occupational health service to which the enterprise may be attached.

(2) The person who receives the request shall involve the necessary and sufficiently qualified medical or other expertise, including occupational hygiene, clinical-chemical, genetic or biochemical expertise, both in connection with the actual examination as well as the interpretation of the clinical consequences of the examination.

(3) Any person who - on the basis of an examination -issues a certificate concerning an employee's state of health and risk of developing or contracting diseases shall at the same time give an evaluation which illustrates the degree of uncertainty in connection with the interpretation of such examinations.

(4) Certificates concerning the results of an examination shall be passed on to the employee of the person who received the request under subsection (1), cf., however, section 9 (4).

Part VII.

Professional secrecy, etc.

11. - (1) Physicians, clinics, laboratories, public authorities, etc. are not allowed to pass on health data covered by this Act to other persons that the person to whom the data relate, cf, however, section 2.

(2) However, passing on of the data mentioned in subsection (1) may take place to the extent that this is necessary in order to serve the purpose. It is further a condition that the passing on of data -
(1) follows from another Act or provisions issued on the basis of such acts,
(2) takes place for the research purposes with the consent of the person concerned, or
(3) is necessary to avoid risks of the type mentioned in section 4 (1).
(3) The employer may not request or receive and use a power of authority to obtain health data.

Part VIII.

Sanctions

12. Persons whose rights have been violated by infringements of the provisions laid down in sections 2 and 9 may be awarded compensation.

13. Any person who acts in violation of section 2, section 3 (3) or sections 9 to 11 will be liable to a fine, unless a more severe sanction applies under other legislation.

14. If the violation has been committed by a company, an association, an independent institution, a fund or a similar body the fine may be imposed upon the legal person as such. If the violation has been committed by the state, a municipal authority or a municipal association, the fine may be imposed upon the state, the municipal authority or the municipal association as such.

Part IX.

Commencement

15. The Act shall not extent to the Faroe Island and Greenland.

16. The Act shall come into operation on 1 July 1996.

Given at Christiansborg Castle, 24 April 1996

Under our royal hand and seal

MARGRETHE R.
/Jytte Andersen

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Genetic pre-employment test: the sociological aspects

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Member of the Committee of ethics of palliative care at theCentre of Aid for the dying - Brussels. Member of the Committee of ethics of the Fédération des Maisons Médicales - Brussels. Member of the Commission on "Bioethics" of the League of Human rights - Brussels.

I have been invited to give you a sociologist's view of genetic testing in the workplace. We are in agreement that this matter is more than a scientific one. Dr Van Damme reminded us very appositely of the limits to these tests in terms of reliability and validity. That brings an essential element of reality to the consideration of this question, both in ethical and in sociological terms.

Yet the intrinsic qualities of the scientific instrument are not the primary concern. For the sociologist, genetic testing is the product of a social activity, research organised socially and at the same time it is an application, that is to say, it enters a social milieu, in this case the world of work. It has an impact on this milieu and partially changes its basic rules, thereby involving other levels of the social situation and even the most fundamental and democratic principles of the community as a whole.

When I say that genetic testing enters a milieu, I am of course speaking metaphorically. What I mean is that genetic testing and its scientific content are seized upon by various groups who are guided by their own interests.

Employers are potentially interested in an instrument which will provide them with an efficient and cheaper work force because genetic testing is believed to select workers for the jobs which suit them and/or to select only the most resistant workers, thus limiting absenteeism and healthcare costs. Then there are the workers or job applicants who could be subjected to testing and whose employment prospects may depend on such an instrument to a large extent. The results of testing could also affect workers' immediate families, who would thus become involved in spite of themselves. Then there are the medical officers who could carry out the tests and thus have critical information on the workers and their families. Politicians are also involved, for in the course of their legislative activities they may introduce, defend or promote a model of society based on certain principles.

All these categories of people invest such univocal genetic tests with various kinds of social significance. This interests us sociologists in that the resulting interactions enable us to understand some aspects of society at a given moment. For the most part the sociologist's work consists, at least theoretically, in observing and analysing these interlocking levels of meanings.

Each of us gathered here is supposed to meet certain expectations: scientists must determine the predictive value of the tests; lawyers must establish the rules and legal framework at national and supranational level; we also have experts on ethics and spokesmen for employers' and workers' organisations. What about the sociologist? Everything here (the moral references, the legal framework, the positions of the social partners, the scientific content) has relevance for the sociologist. I do not claim to give you an overview of all these complex and interweaving levels. I am simply going to give you my views as a sociologist, which I hope will be mindful of the overall social context in which genetic testing affects the world of work.

I am restricting myself in that I am not going to deal with genetic monitoring or the techniques designed to confirm the diagnosis of a specific disease. I shall focus my attention on genetic screening, in particular at the time of recruitment. I am going to speak about the tests which determine susceptibility to a disease in the event of exposure to a risk in the working environment; Dr Van Damme outlined the predictive value of these tests, which is generally poor or even very poor.

Let us recall, in the first instance, that a study carried out for the Office of Technology Assessment (OTA) of the US Congress in 1990 showed that such tests were rarely used by American firms. According to a 1999 report from the British Human Genetics Advisory Commission (HGAC), widespread use of genetic testing had not yet been made by employers in Europe. However, there is one exception: the UK Ministry of Defence requires aspiring military pilots to undergo genetic screening for sickle-cell anaemia. This is the first occurrence. The positions I mentioned earlier are thus forecasts and do not relate to actual practice.

The social context to which I shall refer (another restriction of my point of view) is provided by the constituent and sometimes constitutional principles of our European States and by the social policy guidelines which the European Union appears to have decided to follow. I have three frames of reference.

1) The States in question base their laws on a straightforward principle: protection of the weakest elements.

2) These States have fairly advanced social security systems which are now being privatised to varying degrees. Voices have already been raised against the first effects of this dismantling of public insurance schemes.

3) These States and the Union which they make up are looking afresh at their relationship with the business world and the strategies to which the latter resorts when it is liberalised in the name of flexibility, deregulation, etc.

The matter of genetic testing should be seen against that background, which is not without an ethical content, as you will have been able to judge immediately.

Let us begin with the first assertion: these States base their laws on a straightforward principle: protection of the weakest.

Most national laws and the European directives on health and social security are based on the same principle.

They protect the health and safety of the workers and third parties rather than the employer's interests. From this premise there frequently arise two obligations:

- protection is primarily collective i.e. it is the responsibility of the employers to do everything to make the workplace risk-free for all workers, that is, for any worker irrespective of his individual characteristics, genetic or other. Not only is this collective dimension important, it takes precedence over all others;

- individual protection takes second place i.e. after it has been shown that the employer cannot remove all the risks. That is the reason for medical examinations on recruitment. The worker's state of health is evaluated in the light of the risks which he could meet in the job offered to him. The results of the examinations are confidential. The scope of these examinations varies and is sometimes debatable, but they appear to have a common purpose: to protect the worker's health while not jeopardising his chances on the labour market. The concern to uphold the right

to work is also reflected in the rules relating to medical supervision: if a worker is deemed unable to perform his job, the employer is required to assign him to another job where his health will not be in danger.

Under the most protective laws, medical examination is compulsory and very widely accepted as such, since the risk is clearly established, as is the link between that risk and certain states of health. That brings us to the specific nature of genetic testing. It only detects a predisposition, a virtual state of health some say. Genetic testing is a problem for that very reason. In its Opinion No 46, the French National Advisory Committee on Ethics (CCNE) states, that "the use of such tests should not be authorised since, as long as the disease has not manifested itself, there is no inability to work".

Who can deny that conventional medical examinations on recruitment have a discriminatory effect? But this effect is usually accepted because it is offset by the provisions on medical protection. The same does not exactly hold for genetic testing. These tests do not provide the same protection in that none of them which pertain to the work environment can predict with certainty that the person declared "positive" will in fact develop the disease. The protection afforded is purely hypothetical.

But there is more. Not only does genetic testing not provide the same type of protection but it would tilt protection strategies to the detriment of collective measures. Thus, if genetic testing made it possible to select only applicants who did not present a predisposition to certain diseases, employers could be tempted to stop investing in collective prevention measures. Workers declared fit for work would be considered as predisposed to withstand the disadvantages of their work station and thus the work environment would deteriorate generally.

Compulsory medical examinations on recruitment constitute an application of the principles of equality and solidarity on which our European countries base their social security systems. This brings me to my second frame of reference. The labour laws which are linked to these systems give priority to the principles of equality and solidarity over autonomous decision-making. The specific nature of genetic tests and the "virtual" nature of what they reveal lead some people to think that they should be distinguished from conventional medical examinations by requiring the free and informed consent of the job applicant, i.e. his explicit and formal agreement given in full knowledge of the facts. This is required by the CCNE, by the Council of Europe in its Convention on Bioethics, and by UNESCO in its Declaration on the Human Genome. It is an integral part of a wider debate on how to apply the principle of autonomous decision-making to these matters. This debate relates not only to whether job applicants should have the choice of undergoing tests or not but also to whether he or she should be informed of the results and/or draw the consequences therefrom.

Incorporating the principle of autonomous decision-making into social security legislation and making it compatible with the other social security principles are not straightforward tasks. I would like to illustrate this difficulty with two examples drawn from the paper which Dr Van Damme and Dr Casteleyn published in "La Medicina del lavoro" entitled "Ethical, social and scientific problems related to the application of genetic screening and genetic monitoring for workers in the context of a European approach to health and safety at work" (cf. the name of the European project which they coordinate as part of the Biomed II programme).

The questions posed are as follows:

- Does the autonomous decision-making principle sometimes paradoxically deprive us of freedom?

- Is the individual freedom of the worker in these matters compatible with the interests of workers taken collectively?

- Is this principle not in open contradiction with the spirit and letter of the rules and legal provisions adopted with a view to protecting workers as I outlined above?

First example

An employer is forbidden to assign a person to a post where he could be at risk. The employer must find a suitable post for the worker. The aim of these provisions is to force employers to adjust their jobs to the workers and not vice versa. What would happen if the applicant was entitled to accept or reject genetic testing? The person who refuses the test could be taken on occupy a post where he would be at risk thereby liberating the employer from his vital obligation to eliminate the risk. Inversely, the person who accepts the test and is recruited on the basis of the absence of a predisposition would limit the autonomy of the other applicants who exercise their freedom by refusing the test on the very legitimate grounds that it is for the employer to eliminate the risk and not for the worker to adjust to it.

Second example

If the principle of autonomous decision-making were applied in this specific case it would threaten the social protection of the worker or groups of workers. A worker would be entitled to an invalidity allowance owing to an occupational disease only if the incapacity for work was not intentional. If he refuses genetic testing and then develops a disease linked to genetic characteristics, one could legitimately retort: "Did you not have the choice"? What about protection of specific groups such as pregnant women? Can the individual be left a choice that would harm such groups on the labour market or call into question the protection which they enjoy?

What exactly is the choice? Can one speak of freedom of choice where a job applicant is in a state of economic dependence? For many, necessity makes the principle of autonomous decision-making superfluous. This appeal to individual liberty could be seen, especially in the world of work, as a new attack on workers' solidarity, which is already very diminished if not threatened. This brings me to my third frame of reference.

I feel that Europe's position on the matter, as adopted by the European Group of Advisers on Ethics in Science and New Technologies, must take into consideration the overall socio-economic situation which is characterised by strong tendencies to the deregulation of labour relations and working conditions: closures, relocation, staff cut-backs, increases in workload, deterioration of the social climate, dismissals on the grounds of force majeure... I could go on. Within the Union numerous voices have been raised, some for a long time, to call for the establishment of a social Europe.

Given the present state of scientific knowledge, the inclusion of genetic testing among the medical examinations conducted on recruitment can only be for purely selective purposes and can only appear to workers as a symbol of the intensification and extension of selection practices, reflecting and accelerating the deterioration (deregulation) of the employment situation.

Some see the stress put on genetic testing at work as an inversion of priorities, a reversal of public collective responsibility based on solidarity. Instead of creating a healthy and risk-free working environment for all, genetic testing will replace collective responsibility with individual responsibility and a situation where individuals must choose between adjusting to a context in which they are at risk and removing themselves from that context.

Is this reversal of priorities desirable? Should it be resisted? Resistance to genetic testing on recruitment is not tantamount to resisting genetic science as such.

In terms of preventive and therapeutic medicine, genetics holds out promises which make us hope for massive investment in its development. In time, workers should reap all the benefits. The resistance referred to here is a reaction to the way genetic testing is being applied to the social situation, to an employment market where traditional forms of solidarity are growing weaker by the day.

As long as genetic testing does not prove to have satisfactory predictive value, the social context requires that testing be refused on recruitment. Should workers be kept ignorant of these tests? Where the answer is no, information in the form of genuine "genetic advice" should be given solely by the medical officer, the only person in the firm to be informed of the results if the applicant decides to undergo the testing. Testing should be carried out in approved units and regulations should prevent the applicant from communicating medical information to the employer. All this also requires that the medical officer should enjoy absolute independence, an independence some people would question because the doctor is paid by the employer.

What should be done if genetic testing satisfies scientific criteria? Should the principle of autonomous decision-making come into play? Should the worker be given the choice to undergo testing or not, to be informed of the results or not and to draw or not draw the conclusions? Autonomous decision-making should remain a fundamental principle in many areas where genetics is applied: therapeutics and research. But these are clinical rather than industrial contexts. In industrial medicine we are faced with specific factors which are bound to weigh on the formulation of an ethical position. In particular, there are the economic constraints which impinge on freedom, or what we idealistically see as freedom. Freedom is always an imperative, a moral guide but in reality it is always in some ways subordinate to the constraints imposed on the persons concerned. Thank you.

ROUND TABLE DISCUSSION
(Following individual presentations)

Ms Lenoir (to Mr Lebeer): Thank you for having launched the debate and said that the issue we have to deal with should be seen not only in the context of developments on the labour market but also in the context of what is now being called the new economy. This is leading companies to focus essentially on financial strategy involving rationalisation of human resources and the reduction of staff with increasingly intermittent careers for the employees. In order to set the context for this debate I would like to make a couple of introductory points.

Firstly, this discussion is already taking place in a number of fora although the genetic tests, apart from pre-natal diagnoses, are not yet widespread and they are not yet in use in the workplace. They are, however, to a certain extent, already in use in the United States.

Secondly, genetic tests in predictive medicine or diagnostic medicine will enable us to identify either individuals or population groups who are in good health, but who might be carriers of certain genetic mutations which can bring about future handicaps. This is what could be termed new medicine or tomorrow's medicine which is half way between diagnoses of prediction and selection and discrimination.

Thirdly, this is a political subject as well. It is clear that genetic testing in the workplace will have an impact on workers' rights. All of this is very relevant to present reflections on the Charter on Fundamental Rights the European Union is working on at the moment. Following a request from President Prodi EGE is associated in this work. I was recently at the meeting in Portugal attended by the Portuguese Prime Minister and the main subject was the Charter. In discussion the social dimension of Europe was particularly highlighted. At this stage we do not know whether it will become a part of future Treaties of the EU but we do know that the Charter will be designed to establish the values that underpin the structure of Europe.

Indeed, the issue we are debating today concerns a number of far-reaching questions so I propose we start with questions on scientific matters and then continue with ethical, legal and sociological aspects since these are difficult to separate.

M Sorsa: I would like to put forward three main questions for discussion.

- Are genetic tests really something special?
- Is genetic test-data part of medical information that should be linked to proper genetic counselling?
- Are there any examples when genetic testing should be allowed at work?

It is important to discuss firstly the complexity of the terminology and people's viewpoints. It is important to separate genetic monitoring from genetic screening. Genetic monitoring has been practised for several decades already, especially in analysing radiation. Genetic monitoring is being used in exposure-reassessment for populations, for example in exposure to benzene, where it has been found relevant to make a major change in the concerns about exposure limits. It is of major importance with exposure to ethylene-oxide, Cancer causing agent, and its consequences. Genetic monitoring involves groups of people, not individuals, therefore the ethical issues are perhaps less important.

Genetic screening or genetic testing is on the contrary, more problematic when it comes to ethical issues. There are two major directions, diagnostic testing and predictive testing. Diagnostic testing is used for health purposes, for diagnosis of genetic diseases. Predictive testing is under discussion, and here we are dealing with future possibilities. I agree with Linda Nielsen's point that good legislation is something, which must be prepared for the future development in this area.

The future development of microchip possibilities for testing different combinations of genes, which might or might not be involved in the environment gene interactions for disease, is our special concern. There again I agree with Ms Nielsen's clear statement that genetic testing should be restricted towards health purposes only. There are actually only a few cases, very unusual exposure situations where the occupational environment can not be really safe for everybody. I think that even in such extremely rare situations pre-employment genetic testing should not been performed. But I also think that we should allow that possibility, in these very rare and well-defined cases of genetically susceptible individuals where the exposures are related to DNA damage for instance in order to protect worker's health and offer him another job with the same employment benefits. On occupational health, the promotion and protection of health and safety for the workers, is the most important aspect.

The great enthusiasm among researchers of genetic occupational toxicology is now focusing to metabolic polymorphism. Mr Van Damme pointed out some of these metabolic genes which really make a difference in exposure of conditions but the problem today is that genetic tests are neither well validated, nor predictive enough to be used in employment situations. However, the legislation is needed because this area is developing so quickly that we might end up with the situation of the selection of the fittest and on a false basis.

Mr Van Damme (to Prof. Sorsa): I would like to respond to your questions. On the first, whether genetic testing is special, from a predictive point of view, I would say that genetic tests are less predictive in occupational health risks than traditional testing.

I agree that specific regulation regarding genetic testing should exist but it is important to identify which ones. It might be possible in the near future for everybody who has some ability for laboratory testing to do genetic testing as well. This is not the case with more traditional testing which requires medical training. The crucial factors are who does the testing and who decides what the tests mean. Ms Nielsen said that people who are trained to do the tests are the only ones who do it. I would say that only people who are trained to assess the relevance of these tests should carry them out. And this is something very different and I would like to know how this problem has been solved in your country, Ms Nielsen.

In Belgium and France for instance, occupational health is basically in the hands of medical profession in collaboration with other disciplines. This multidisciplinary approach together with 4 years training in order to be able to assess this correlation between exposure, risk of desease, work and person's susceptibility allows precisely the negotiation with the job candidate.
(to Ms Nielsen) Who in Denmark decides if the test is relevant? Is it the employer? Most employers are not trained to decide whether a test is relevant or not.

The second question was whether genetic test-data should be treated as medical information or not. I believe it should, but its prime purpose should be the protection of workers.

Ms Gebhardt (to Mr Van Damme): You said that you thought that genetic screening should be outlawed, unless there was a very close correlation between the test of the screening and the particular disease or the atmosphere in which the worker would be working. I understood that it would be rather difficult to carry out this type of screening because the tests are not reliable. However, having said that, do you think that it might be possible for these tests to become more accurate and acceptable following technological progress? Alternatively, do you think that the interference between genetics and the environment is so great that it is impossible to separate the two? Therefore if there is a great deal of technological progress it might not be possible for us to come up with anything approaching certainty as regards the result of these tests.

Mr Van Damme: The relevance of a test depends upon why it is used. If used for exclusion there is no single genetic test, which would at this point of time be relevant for excluding workers at pre-employment examination. Not one single test. And it is quite unlikely that in the near future there will be tests that are relevant for excluding persons at pre-employment examination. It all depends upon who is using the test and why. If the user of the test is well trained and uses the test to protect the worker, then some of them may become useful in the future. The problem is that very often, especially in the standardisation approach a deterministic connotation is given to a gene test. But a gene test could be relevant for orienting periodical medical surveillance, and not for excluding persons at pre-employment examination.

Ms Lenoir: However things are changing and it is very important to realise that. For instance, when medical aptitude tests are carried out do you ask candidates about their family's medical history? Do you ask for example a pilot if anyone in his family died from a heart attack or from cardiovascular disease?

Mr Van Damme: Recently there have been some arguments in the genetic world, that some of the very extremes on the cholesterol dependent diseases, like heart attack, may be predictable by some genetic tests. Family analysis is usually done in countries where occupational health physicians deal with occupational health. But all this becomes a matter of negotiations. Maybe I should give the advice to the candidate not to take the job or to take it. However, it all has to be put in balance at the same time. It must be negotiated with the person.

Ms Paula Martinho da Silva (to Ms Nielsen): Since you have legislation on this subject in Denmark, I would like to know what were the employers and the employer-associations reactions on this legislation? Secondly, do you do any genetic testing in Denmark and if so, are there any cases or particular consequences of that?

I have a question for Mr Van Damme too. When you make a distinction between susceptibility and determinism, is it correct to think that we are creating two categories of workers? Those who work directly in industries and who are the most exposed, and those who do some intellectual work and are never exposed and consequently will never be submitted to genetic testing.

Mr Vogel (to Ms Nielsen): Denmark is one of the first countries in the European Union to draft its own legislation on the subject. It is the precursor and this fact should be taken into account in discussion. I have three points to discuss.

Firstly I wonder whether the Danish legislation could correspond to the preventative model which we have in the European Community. The European directives and prevention systems in most countries mean that the preventive services are already in place. The occupational medicine plays an important role in it. In the Danish example we have the mechanisms by virtue of which employers may have access to data on workers health but the service's intervention as such is not described or covered by that legislation. I understand that for historical reason Denmark has not had such developed branch of occupational medicine. Therefore this specificity should be taken into account in future drafting of European legislation on the subject.

Secondly, in certain specific circumstances the Danish employers are entitled to have access to some information on health. In most other European countries employers do not have access to employees' health data in any circumstances. They may have information about the conclusions which occupational physicians may draw following a medical examination. But the employer has no direct access to medical information and this is very important distinction that should be also taken into account in drafting of European legislation.

The third point is the possibility offered by the Danish legislation to derogate from the general provision on a non- access to health information as regards the agreement with any company on the access which is possible when the information is related to the running of the company. Let's take an example of a company, which is afflicted by a very serious problem of absenteeism. In these circumstances, would it be possible for two sides of the industry to bargain together to provide certain information to employees in order to bring down the absenteeism rate. I am representing here the European Trade Union Confederation and I certainly would have not gone along with any Trade Unions participating in such a dialogue. As it would be attempting at violating essential workers' rights.

Ms Nielsen: The first question was whose decision is it? There is now legislation in this area, so employers cannot ask whatever they want. If they ask information which is not allowed there are sanctions like fines.

Secondly, who will be performing these tests? The request to undertake investigation should go through the employee, and the employee is the one who is choosing whether to use his or her physician or the occupational health physician who is dealing with this at work. There is a specific regulation saying that the one who requests the testing shall make sure that there are necessary and qualified experts to do the tests. It is also expressly stated that in the evaluation the degree of uncertainty by the interpretation of the investigation should be told to both employee and employer.

Thirdly, what were the reactions from employers and employees on this legislation? I think that we can say that the employees and their organisations are mostly satisfied with the legislation, while the employer and their unions are not so pleased, because it puts restrictions on their right to question the candidates. They point out two critical points; one is that it is not clear what is allowed to be asked, and what is not. The other is that they think it has become too restrictive in the sense that they are not allowed to ask health-information that they used to ask, even if it is not in connection to genetic testing. The practical consequences are that fewer questions are being asked concerning future health issues than before.

It is clear though that some employers still ask more than it is allowed by legislation but I do not have any figures to show. There is the Board also which is dealing with questions and specific cases. I must add that something specific has been done in cases where the working environment was at stake. Even if you ask questions which are not allowed concerning the pre-employment, you may carry out the investigation aiming at improving of the working environment in order to prevent sufferings. It was important to make that distinction while drafting the legislation as a lot of work has been done in Denmark concerning the working environment.

Confidentiality of information is protected by a clause. Doctors are not allowed to give any information they have about the employee. That is the reason why only the employee can ask questions, get the answers and pass them to the employer.

Another clause I would like to mention is the one saying that the employer is not allowed to ask for a mandate to get the information. This is of great importance concerning the insurance cases. In those cases that is what has been done very, very often. But this is not allowed anymore.

Ms Lenoir: This is very interesting and I think there are fairly major breaks in this legislation. As far as I remember, from the French situation, the occupational health physician is an employee of the undertaking with a privileged status, but I think that in the French situation, it would be inadmissible for the employer to have any access whatsoever to medical data. The occupational physician can say that one would be a likely candidate for this or that post but that does not reveal any information. The same applies to insurance companies' medical advisers. They determine the premium to be paid on the basis of medical data being at their disposal. But the medical adviser is not entitled to have direct access to individual medical questionnaire. He has to do it via another questionnaire so there is a double filter. In

France and I think in Belgium as well it would be quite inconceivable for any employers to find whatsoever about the medical dossier of their employees.

It is also a question of confidence in labour-relations, but in France we have virtually never had something like a statement of inaptitude. We have to strike a balance and we have to have very specific review of various member-states legislation as regards medical tests on employment or even regulatory checks throughout employment.

Ms R. Kangasperto: I would like to highlight the complexity of the relations between employer and employees and between employees and health-care professionals. This is where we first of all need some rules. Health-care professionals have some laws, including also their duty to ensure the confidentiality, and that is why we have established three-party group in Finland of which I am the chairperson. It consists of the representatives of Ministry of Labour, Ministry of Health and Social Affairs, Ministry of Justice, Members of Office of Data Protection Commission, different social partners etc. We have reached an agreement and we are going to suggest that we need some kind of regulation on genetic testing in the workplace, this means in particular labour-law concerning the situation between worker and employer. According to this proposition the employer has no right to require or to decide that the employee or the applicant has to take part in genetic testing; the employer has no right to know whether such examination has been made and that means that the employer cannot get the information about employee's health. That also means that the use of genetic information by the employers is prohibited and will be sanctioned, as is the case in Denmark.

Ms Ronchi: About two weeks ago the OECD organised a workshop on genetic testing, and I am very pleased to see some of the topics that we were not able to address, being discussed here today. We took a very broad approach and we addressed the commercial aspects, economic aspects, human resources aspects, access-issues and laboratory quality assurance. We had an interesting debate about the various approaches to counselling across OECD-countries, and finally we looked at issues regarding data banking and the current legislation in OECD-countries on privacy and confidentiality.

The recommendations coming out of this workshop, are centred around the mandate of the OECD, and the role that the OECD may play with the WTO in particularly addressing human resources issues, standardisation of tests, and other issues that are at the centre of some of the pre-occupations of the WTO.

A major issue that was discussed during these three days in Vienna, if genetic tests are something special, was difficult to come to terms with. 50% of OECD-countries do treat them as different, while other 50% still have it in their legislation as an expansion of other types of medical data and tests. Another point that was raised was that we need people that are trained to assess the relevance of a test. However, there are several problems, first, what does relevance mean, and second, the gateway to these tests are changing because of the pattern of commercialisation. In the United States two bodies regulate tests: CLEA and FDA. CLEA does not address the issue of clinical validity and utility and the majority of genetic services and genetic tests, which are today on the market, have gone through CLEA. Our focus will be rather to address standards in quality assessment of laboratory services. In validation of tests there are very different modes and qualities around in OECD-countries. The percentage of failures and false negatives surprised many of us. We discussed a possible compatible, electronic information systems, and the so-called "bioinformatisation" of genetics and genetic tests. We considered the possibility of SMART cards allowing people to bring their medical history with them wherever they go. But this is very delicate and might require not only the extension of some already existing legislation on privacy, confidentiality and electronic data sharing but also the need to provide the medical community with comparable terminology.

Ms Lenoir (to Ms Ronchi): Are there any indicative lists of the patents which have been granted to the tests?

Ms Ronchi: There have been only five genetic tests kits, which have been approved today by FDA. In Canada no genetic tests kits have been approved. However, the most of the American companies that are developing this technology are also developing a type of genetic service and this is of particular interest. There are two types of a purchase: they either facilitate access to counselling and have partnerships or they do provide counselling.

Ms Tempel: At the Bioethics Convention a few years ago, the question of how the article about predictive genetic tests should be drafted was very much contested by some of the negotiators. The concern was to state clearly that predictive testing should be performed only for health purposes or for scientific research linked to health purposes. So, there is a kind of rule that is already existing although one of the very striking legal questions remains: what is covered by this definition?

Referring to the EU Charter of Fundamental Rights I would like to point out that not only the social rights are very much discussed but also something which is new on the level of European Union: right to life. The proposed article mentions the right to genetical integrity and non-discrimination. This is something that also has to be linked with the issue as it is discussed today.

My more ethical remark relates to a document published two years ago by the Protestant Church in Germany and the German Bishops Conference. Under the label "How much knowledge is good to have?" they put forward criteria for clinical use of predictive tests. My question is whether we can take these criteria and apply them to labour conditions without any changes?

Finally, I am very much struck by the free movement of workers in the global labour market. What it does imply to take a SMART card with you?

Ms Lenoir: I agree that we have to emphasise the importance of mobility, because in Europe working mobility at present is not very high. One of the objectives of the community funds was to help countries to create employment, but if we do not have any kind of harmonisation of social security, it would be rather difficult to promote mobility. Pension rights and social security rights have to be ensured in every country.

Mr Whittaker (to Ms Levitt): It is clear that genetic screening for susceptibility gives results that are mostly of limited predictive value, and the consensus of our discussion here today seems to be that on the basis of this, there should be no requirement by employers for pre-employment genetic testing. I would like Ms Levitt to consider that if there is a statistical predictive value for a particular genetic test, should the employer have the duty to notify the potential employee of this, and to provide the relevant genetic test for the employees to provide for themselves whether to accept employment on that basis.

Ms Levitt: An easy answer would be that if it only has a statistical predictive value should be employed better in the test in the first place. We said before we should only be doing the test if it was directly related to particular job. That will be very narrow range of tests. I think is a very difficult question, because one wants to offer choice to the people. However, lot's of questions about whether there is treatment available and whether there are any benefits in knowing, and finally the question is who should decide that. We already know that people who are at risk decide not to have the tests that would have given them the definite results. It is very difficult to protect people's right not to know, once the tests are available.

Stephan Winter: The Human Genetics Group in the Council of Europe attached to the Convention on Human Rights in Biomedicine, which came into force on December 1999, addressed the medical and scientific aspects of genetics. We are now working on occupational aspects and insurance matters. In the European Convention on Biomedicine, the article on non-discrimination says “no one should be discriminated on grounds of his or her genetic heritage”. There is also the binding of the genetic testing to the health purposes and to the adequate genetic counselling. But there are other important provisions in the Convention such as the informed consent principle, the right to know and the right not to know personal data, the legal principle of sufficient public information etc.

I have two remarks to make on the issue. Firstly, there is also a double side of coin problem in predictability. The so-called sensation seeking genes are a good example. For instance, genes can measure some attitudes of the persons reacting to extreme sports. But the same genes responsible for this make persons to be disposed to suffer from depression in later life. You cannot predict what is the outcome for the person, if you have this measurement.

Secondly, genetic chip technology should not be underestimated. I consider that the pharmacogenomic will be obligatory in 5 to 10 years for doctors while measuring genetics profiles of patients in order to avoid side effects of medicines.

Alastair KENT
M.Phil,
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The patients'association point of view

Alastair Kent has been the director of the Genetic Interest Group (the national alliance for voluntary organisations, charities and support groups for those affected by genetic disorders) since 1993. He has worked in the voluntary sector for the last fifteen years with a range of charities concerned with the development and provision of services to people with a wide range of disabilities.

Prior to joining the sector he worked for three Local Education Authorities, initially as a careers officer, but moving to work with school leavers with disabilities and/or learning difficulties eventually playing a county wide role in North Yorkshire, where he was responsible for coordinating the contributions to meeting the needs of these young people from a range of public, private and voluntary organisations.

His first degree is from Cambridge, where he followed the Natural Sciences Tripos. He also has an M.Phil based on research drawing on aspects of his work with school leavers with learning difficulties.

Introduction

Before considering the possible uses or abuses of genetic testing in the workplace, it is necessary to be clear about what, precisely we are talking about.

"Genetic testing" can be used to describe a variety of different behaviours and it can be used in a range of different circumstances, some of which may be entirely appropriate and some of which may render the individual tested vulnerable to unfair discrimination.

At the simplest level, genetic testing is used to describe the scientific analysis of either DNA or of chromosomes to detect changes in particular genes that are linked to observable changes in the phenotype of the individual tested. These changes may be caused by the observed changes (as in muscular dystrophy or Huntington's Disease) or they may predispose the individual to develop changes in the presence of other, environmental factors (as in the case of most forms of cancer or breast disease).

However, "genetic testing" can also be applied to describe differences that may be drawn from other types of investigation, such as a knowledge of family history or the result of biochemical tests or other procedures such as ultrasound or MRI scans. These other procedures are usually but not always less precisely interpretable than are the results of a DNA analysis, nevertheless they reveal something about the genotype of the individual in which they are discovered. Pragmatically, it may be easier to separate the former from the latter, but logically there is no reason to do so when thinking about genetic testing in the context of the workplace.

Testing by employers

Firstly, it is important to emphasis that this is not currently an issue anywhere in Europe Nor, as far as I am aware is there widespread use of tests in the USA. When the UK Human Genetics Advisory Commission looked for examples of workplace related genetic testing, the only example they could find was the screening of air crew for sickle cell carrier status by the Ministry of Defence (in the apparent belief, unsupported by evidence) that this was associated with potential problems under extreme situations when flying.

Although this is a situation where the action seem to be driven more by myth than reality, it does highlight a set of circumstances in which it might be appropriate to introduce workplace genetic testing.

Suppose that a causal link has been identified between a specific aspect of a particular job and an identifiable mutation or mutations in a specific gene or genes that results in a significant health problem for those with the mutation or which creates a significant hazard to third parties as a direct result of the activities of the person carrying the mutation in the presence of the risk factor.
Suppose further that the risk factor was integral to the job, that it could not be "designed out" and that the exposure could not be avoided by the application of good Health and Safety practices. In such a situation the offer of a genetic test might be an appropriate one to make.

However, in making the offer, the employer would have to be aware of compromising the employees' rights.

Tests should always be voluntary and those contemplating them should have the opportunity to receive good, unbiased information and appropriate pre- and post test counselling if they wish it.

Testing should not be accompanied by inducements or penalties for the person tested and no adverse inference should be drawn from an individual decision not to be tested. However, in the advent of a test being offered and an employee refusing it there may be a question of reduced liability for the employer, as the affected individual had the opportunity to find out the risk they were facing.

Employees who test positive should normally be offered equal value alternatives within the organisation.

It must be stressed that the circumstances under which it would be legitimate to introduce genetic testing are going to be very rare and extremely specialized. It would not be appropriate to introduce employee screening for, say breast cancer predisposition genes on the grounds that an employer might wish to avoid the perceived risk of employing someone likely to be at greater risk of health problems in the future.

The time between the point of testing and the likely emergence of symptoms must also be taken into consideration. Testing at the age of 18 for a condition which may not emerge for many years might unreasonably blight a career from the start - although if the ultimate impact was a major one it **might** be legitimate to consider it, even if only to create the opportunity for anyone who thinks they may be at risk to seek information and counselling.

Testing for employees

The introduction of genetic testing for health reasons may, under certain circumstances be useful for employees in terms of facilitating their career planning or enabling them to avoid certain types of occupation. However it should not be assumed that there will ever be many circumstances where genetic testing may be significant for planning a particular course of education and training.
Genetic testing should, rightly, be considered in the context of health care decision making and as such undertaken in a clinical, rather than a workplace context, even if the information concerned might be relevant for the individual to apply in other situations.

General Issues

The likelihood that genetic research, as it progresses, will reveal significant numbers of genes which are highly penetrent and which result in substantial employment related health problems is small. Without a family history of a particular disease, there is no reason to assume that there is the potential for trouble lurking in our genotypes. Even if chip technology makes extensive genotyping a technical possibility, it must be questionable whether the information that results from such genotyping will be significant for employment or any other purposes.

Therefore, before thinking of introducing work place testing, the onus on those who want to see it in place must be to prove that the test(s) suggested are accurate, valid, reliable and significant in the terms laid out above.

It must also be stressed that genetic test results have familial implications and the mechanisms set up around any test procedure must respect the clinical and familial confidentiality of the individual and his or her relatives that apply where genetic testing and counselling are carried out in medical surroundings.

Given that the decision to introduce genetic testing in the workplace might be considered to be a legitimate avenue for an employer to pursue at some point in the future, there ought to be a regulatory system in plan to confirm the legitimacy and the appropriateness of the decision and of the arrangements set up around the proposed procedure. The UK's Genetics and Insurance Committee might prove a useful model to copy and develop. Before an insurance company can consider using genetic test results when underwriting an application, the condition, the insurance product and the significance of information must be established. However, in insurance the test once approved can be applied by any company in respect of the products for which it is deemed appropriate. In employment a case by case approach would probably be essential.

Conclusion

The prospect of genetic testing becoming widespread in the workplace seems remote. Employers would be well advised to exercise caution, before considering this step, as the results of any such programme are likely to be inconclusive, especially when the costs of such a programme are calculated - and must be borne in full. It would be wrong to let the additional costs of any workplace testing programme fall on the health care system - through additional counselling or other increased demand for services that might be generated.

This is not to deny that circumstances may arise in which workplace testing is legitimate and appropriate, merely to say that it seems unlikely and that there are much more urgent issues facing disabled or chronically sick people in the workplace and also those currently fit and able bodied, which arise out of discrimination practices or poor health and safety, that are producing inequality and disadvantage now. If they were to be addressed effectively, then the likelihood of genetic testing becoming widespread would be even more remote, as the contribution it might make could be set in perspective, as would the cost that it would create.

If the situation were to change we could predict it sufficiently far ahead to be able to introduce appropriate regulation and/or legislation that reflects the reality of the situation then and not our fears now, which may never be realized.

A watching brief seems to be the order of the day.

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The employees point of view

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The European Trade Union Confederation's view on genetic testing and the workplace

1. Our basic position is that we are opposed to any form of genetic selection of workers. This means that genetic screening based on a predictive assessment of an individual's predisposition or susceptibility (lesser or greater resistance to a specific disorder) must be made illegal in employment relations. The ban must be underpinned by effective, deterrent penalties. If there are to be exceptions, they must be statutory, only on the grounds of the worker's or another's health and safety, and kept under review by the regulatory agencies. Genetic monitoring (ascertaining whether genetic material has been damaged by occupational exposure), on the other hand, can be regarded as an admissible form of medical surveillance if it meets the same acceptability criteria as for all forms of workplace health surveillance. In employment relations, it extends from recruitment (including pre-employment selection procedures) throughout the entire period of employment. Taken in this broad context, the ban on genetic screening should take in employment and recruitment agencies, temporary employment agencies and insurance companies with work-related business (e.g., occupational risk insurance, supplementary health insurance or pensions).

2. Our objections to genetic screening are mainly to do with consistency of workplace prevention policy and protection of workers' individual fundamental rights. The scientific rationale of genetic screening systems is not at issue here.

3. Genetic screening is unlike most other forms of health surveillance because it is chiefly about predicting susceptibility or predisposition. It does not say whether the individual examined is fit to do a particular job in safe and healthy conditions, nor does it detect genetic damage from workplace exposures that would justify taking preventive action. There is enough evidence to show that, in the absence of specific rules, some employers will in practice use predictive medicine methods which no doubt fit in with some "human resource management" ideas but are at odds with preventive principles (one of the most disgraceful being HIV testing, which has denied many people jobs without the slightest justification in preventive health terms).

4. The preventive principles enshrined in International Labour Organisation Conventions[1] and Community directives[2] in particular, are based on a strictly-defined hierarchy of the measures to be taken: avoiding risks, evaluating the risks which cannot be avoided, giving priority to collective protective measures to combat or reduce risks at source, etc. This is the general setting in which health surveillance takes place. It has nothing to do with employee selection.

5. Also, workplaces contain a combination of different risk factors, each one of which may be linked to different potential disorders. So any judgment of a worker's fitness based on genetic screening must be open to doubt, since it can only ever focus on a very specific aspect of the work-health equation which links a risk factor to a disease. Increasing the battery of tests may only produce inconsistent results.

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[1] Specifically, Occupational Health Services Convention No. 161 and Recommendation No. 171, the document adopted by a tripartite expert group, *Technical and ethical guidelines for workers' health surveillance* (MEHS/1997/D.2), and the *ILO Code of Practice on the Protection of Workers' Personal Data*, which says that "genetic screening should be prohibited or limited to cases explicitly authorized by national legislation".

[2] In particular the 1989 Framework Directive and its supplementing individual directives (the main individual directives with relevance to genetic testing are Carcinogens Directive 90/394 and Chemical Agents Directive 98/24).

Testing, for example, might reveal one genetic trait which made an individual more susceptible to developing asbestos-related mesothelioma, and another which suggested a probable greater resistance to asbestosis risks. This potential drift towards predictive medicine, therefore, makes it vital to reassert the employer's main safety obligation to provide working conditions which do not put the health and safety of all workers at risk. This duty is bound up with the aim of making employment conditions open to everyone of working age.

6. The "statistical facts" of a genetic screening-based assessment of individual susceptibility has nothing to do with the "individual facts" of a worker's past health history. That a particular genetic trait puts someone in a group statistically-defined as presenting an above- or below-"average" risk is no grounds for denying their right to work. This fundamental right not to be discriminated against on the grounds of genetic make-up is also bound up with protection against other possible causes of discrimination, in that genetic traits are rarely evenly-distributed between men and women, different ethnic groups, etc.

7. Particular features of the employer/employee relationship demand that wider, specific legal safeguards on genetic screening be established. Workplace health surveillance is not just a matter of free and informed consent. For one thing, national practices (and Community law) make health surveillance compulsory in various circumstances, where the worker has no say in the choice of examining doctor or the tests performed. For another thing, the reality of employer/employee relations largely robs the worker of his independent power of decision, because his consent or refusal to be tested may determine whether he gets or keeps his job[3]. Our considered opinion, therefore, is that decisions about genetic screening should never be left purely to agreement (between the worker, preventive services, employer).

8. We find workplace or industry-wide collective management arrangements no better, because they, too, may undermine individual fundamental rights. Any decision which related not to present fitness but to an estimated future possible state of health, would be a case in point. There is here a fundamental limit on the scope of decision-making left to collective representation bodies (health and safety committee, works council, trade union, joint industrial council, etc.). Government must consult with bodies that represent employees, employers and occupational health professionals, certainly, but we would argue that it must also lay down consistent rules for all workers within a framework which ensures searching political and social debate. In the European democratic tradition, that necessarily involves legislation.

9. All the available evidence suggests that specific rules on employment-related genetic testing must be brought in without delay. It may well be the exception now, but that could change radically as developments are moving quickly. The range of tests available will certainly increase in the next few years. Companies may come under pressure on two fronts:

- A burgeoning market which will seek to make existing tests pay by expanding sales heedless of the social and ethical implications of testing.

- Cost-conscious occupational and general health insurers encouraging employers to screen out the workers covered, or charging differential rates for "high-risk groups".

[3] In the case of an official who refused to undergo a pre-recruitment HIV test, for example, the Court of Justice of the European Communities held that: *"If the person concerned, after being properly informed, withholds his consent to a test which the medical officer considers necessary in order to evaluate his suitability for the post for which he has applied, the institutions cannot be obliged to take the risk of recruiting him"* (Judgement X v Commission, 5 October 1994).

10. Many Community directives already deal with workplace prevention set-ups. Community rule-making powers are beyond question in this area. Article 137 of the Amsterdam Treaty re-enacts the previous article 118A provisions on it. Genetic screening raises questions of principle which could unpick the workplace prevention system at the seams and which do have a direct impact on fundamental social and employment rights. For that reason, Community legislation is essential to buttress and supplement national legislation in this field.

Addendum....

Following the discussions staged by the EEG, we would like to clarify our position on a number of points.

1. Prohibit or protect against discrimination?

Would general measures to stop discrimination on the grounds of disability or health be enough to ensure that work-related genetic tests were used in a way compatible with fundamental rights?

We believe that such measures - although useful and desirable - would not be enough where genetic tests are concerned on two counts:

a) Measures to protect the individual against discrimination have rarely worked in practice due to evidential difficulties. Maternity protection is a telling example. Most EU Member States have made it unlawful to ask a woman job applicant if she is or is planning to become pregnant in the near-ish future. One effect of this may be to encourage lying (because a refusal to answer might be taken as a yes) - a much more effective solution than anti-discrimination measures requiring the unsuccessful job applicant to prove that the employer's refusal was because she was pregnant.

b) The issue at stake is about more than just managing the potentially discriminatory outcomes of gene tests. By their very nature, they discriminate on health grounds. The infringement of equality and individual rights is not justified by claims that there are material health benefits for workers which could only be reaped by the use of DNA tests. A parallel can be drawn here with AIDS tests, whose predictive abilities are much less in doubt than gene tests but are nevertheless deemed unacceptable in employment relations (aside from very exceptional circumstances connected with particular occupational risks).

2. Danish legislation

We do not accept the 1996 Danish legislation as a benchmark for drafting Community rules in this area. It deals with workers' disclosure of medical information to the employer and treats genetic tests as just one of many kinds of medical information. This is partly because the preventive services in Denmark are largely demedicalized, and so the link between prevention and medical surveillance is less evident than in most other Community States.

The Danish legislation

- categorically does not tally with the European model of prevention as established through the Community directives. There is no reference to preventive services, nor the link between medical information and collective prevention activities;
- allows far too many exceptions (in particular, company-level agreements based on the company's operational needs(!), which allows disclosure of information not directly related to workplace health protection, for example, to cut absence rates or change behaviour (drug-taking, drinking);
- is not acceptable to most European countries where employers never get to see medical data, only what they may mean in terms of aptitude;
- is based on the idea of informed consent, which not appropriate to employment relations.

3. Prospective exceptions

During the discussions, I was asked to clarify my position on what exceptions there might be to a blanket ban. Let me first say that, based on the different cases put forward, none strike me as being acceptable from a preventive viewpoint. The most accurate predictive tests (for some monogenic diseases) are unrelated to occupational health. As regards prevention of occupational cancers, for example, genetic selection would not give the selected workers the cast-iron certainty of immunity, and would be socially unacceptable by excluding many false positive reactions and true positive results where there was no proof that those concerned would necessarily fall ill if the proper preventive steps were taken.
Any exceptions, therefore, would have to have strings attached, which might include:

a) a clear link between the genetic test and a disease caused by occupational risk factors which can be neither eliminated nor controlled. Genetic selection must not be used as an alternative to effective preventive measures. Vague criteria, like whether the measures taken are "reasonable", are categorically not enough. All preventive measures technically possible must have been taken to eliminate the risks (e.g., by replacing a carcinogen with another non-carcinogenic substance) or if that is impossible, control them properly;
b) the relation between the identified genetic condition and the disease must not simply be one of susceptibility. There must be sufficient scientific evidence to establish that the individual will contract the disease within a specific time;
c) observance of the general conditions applicable to all forms of medical surveillance at work;
d) an assessment of the severity of the disease without reference to non-health-related considerations (absence, productivity, behavioural choices, etc.);
e) compulsory supporting measures (job guarantees, ban on pre-employment testing, etc.);
f) any exceptions must only be authorized by a public authority and regularly reviewed to see whether advances in prevention techniques have made them superfluous and to control the social use to which they are put (e.g., are they being used to indirectly discriminate according to gender or ethnicity?).

4. Insurance or prevention?

There is widespread debate and some regulation of the use of genetic testing by insurers in Europe. It must be stressed that the rules (or lack of them!) for insurance cannot be a benchmark for occupational health. The entire history of occupational health is a tug-of-war between the insurance and prevention approaches. From the blanket denial of the nexus between work and silicosis throughout the first half of

the twentieth century, to the refusal to recognize the causal link between work and many musculoskeletal disorders, experience shows that occupational health must be seen as an aim in its own right leading to prevention policies, and that the insurance rationale is alien to that aim. It is not without interest to recall that during the early debates on silicosis, one argument advanced against prevention was the purported predisposition of certain ethnic groups[4]. Genetic selection, in these terms, is no more than a more refined and superficially more scientific form of eugenics in the workplace. Certain current developments make it more important than ever to reaffirm that occupational health, and the legal rules dealing with it, must stand apart from the insurance approach:

- the entry of insurers in some Community countries into the field of prevention practitioners (as in the Netherlands and Spain, especially as regards occupational health services);
- pressure, especially from the European Commission[5], for some countries' public/private benefit systems (private insurers in the social security system) to be completely opened up to competition;
- the dismantling of social security systems, leading to an expansion of private, often work-related, health insurance. This is an area where there is powerful pressure from employers to confuse the obligation to prevent occupational risks with a vague policy of "promoting individual health". But, this "health promotion" policy is often an invasion of privacy (e.g., through drug detection programmes) and may lead to health-based recruitment.

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[4] In Wales, doctors sought to refute the work-related origin of silicosis by claiming it to be a simple variant of tuberculosis, and hypothesized a connection between tuberculosis and the ethnic origin of slate quarry workers: "In his 1930 memorandum on the high tuberculosis death rates in certain parts of North Wales, Professor Lyle Cummins cited the work of Dr Emrys Bowen (...) who explained the differences between various districts in Wales in terms of race; the dark long-headed type was apparently more easily adaptable to industrial environment than the fair-haired Anglo-Saxon. Dr W. H. Lewis of the Montgomeryshire Insurance Committee believed that tuberculosis was more prevalent in Western Wales because the Iberian type of Welshman was to be found there". (L. Bryder, Tuberculosis, Silicosis and the Slate Industry in North Wales 1927-1939, in P. Weindling (ed.), *The Social History of Occupational* Health, London: Croom Helm, 1986, pp.108-126.

[5] See Commission v Belgium (C-206/98) concerning incorporation of the 1992 Directive liberalising direct insurance other than life assurance.

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The philosophical aspects of genetic testing: the example of insurance

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His work concerns primarily the problems of responsibility and risks namely in French Social Security System.

As an opening observation I would like to note that in Europe - and maybe beyond - two of the major myths current at the beginning of the 21st century centre round genetics, with all it is supposed to herald in, and insurance with all it is supposed to exclude. Maybe the first thing we need to do is to get rid of these myths. One is the myth that has grown up and been fostered by certain geneticists about what genetic science is going to be able to tell us in the future. This has been christened "geneticism": we will soon be able to know the exact date and nature of our future illnesses even before we are born. The other is the myth that insurance is fundamentally about exclusion. However, the figures, which are not disputed, show that 99% of insurance applications are accepted: 95% with a standard premium and 4% with "increased hazard" premium. The first ethical stance that needs to be taken is to allay fears, dispel these myths and generally take a rather more positive view of things. It is indisputable that genetic research is advancing in leaps and bounds, but it is too early to know what vision of mankind it will yield.

Let us try to describe the problems that are liable to arise where genetics meets insurance. First of all, a distinction needs to be drawn between different types of insurance. Arguments that apply to sickness insurance do not necessarily apply to life insurance. They are not the same type of thing, particularly in Europe where these two types of insurance are governed by quite different ethical and legal requirements. In Europe we draw a fundamental distinction between, on the one hand, sickness insurance, which provides access to health care and is for the most part organised through social security systems, and, on the other, life insurance, which is about individuals managing their assets. Sickness insurance is meant to ensure equal access for all to quality health care. Life insurance cannot be treated in the same way, since people are free to use their assets however they see fit. This is what makes the moral status of the two things utterly different. This is why it is not possible to discuss genetics and insurance in the abstract. Incidentally, legislation on sickness insurance was recently introduced in France to outlaw the use of any genetic testing, but this hardly raises any problems since the nature of sickness insurance is quite distinct.

Given this distinction, what are the principles at stake? On the one hand, there are the requirements of collective ethics and, on the other, the ethics of insurance and the technical constraints it operates under.

I will discuss two major imperatives of collective ethics. The first revolves around the idea of discrimination. Here the question is how to establish when the use of health information or information in general does or does not constitute discrimination. I think it is essential to draw a distinction between what we in the insurance world call "risk selection", i.e. making an assessment, and the concept of discrimination. Our legal systems make a distinction between selecting a person, say, for public office or a job and the point at which this choice constitutes discrimination. The same distinction applies in insurance. The distinction must be made between the assessment of a risk and where this assessment is liable to constitute discrimination. The selection of a risk does not in itself constitute discrimination. Otherwise all insurance would be illegal.

The second issue is the problem of access to insurance, and in particular the status of people who are unable to get insurance. The most common type of case is loan insurance. In France it is now standard practice that when you take out a loan, the bank also asks you to sign up to the collective insurance policy it has taken out for its customers. Since this extremely common-place type of insurance is what actually enables people to buy consumer goods, housing or the tools of their trade, it is easy to

appreciate the difficulties encountered by those who are unable to get such insurance. This is not a question of discrimination, but of solidarity. The question is: where a risk is selected in accordance with rules that, while not actually discriminatory, lead to prohibitively high premiums for certain people, should these people receive some kind of government subsidy to gain access to insurance, something along the lines of legal aid or housing benefit?

These are the two main issues from the point of view of collective ethics: on the one hand, selection and discrimination and, on the other, access to insurance and solidarity.

Now for the ethical and technical factors on the insurance side. The first consideration flows from the fact that taking out insurance means applying to join a mutual insurance scheme and joining such a scheme can only be done in good faith, i.e. people should not seek to exploit membership for personal gain, in particular by concealing facts about their circumstances. This is the fundamental principle governing all insurance policies and is acknowledged by all legal systems.. An insurance policy is a good faith contract *par excellence*: it is wrong to conceal facts one knows about the risk to be insured, since this amounts to not paying one's dues into the scheme and expecting the other members to pick up the tab. Insurance policies require good faith as a matter of justice. The insurer respects this principle by putting a fair price on the risk. If I seek to take out insurance without declaring the facts about the risk I constitute, for example, if I am buying an apartment in the knowledge that I have health problems likely to reduce my life expectancy, then it is clearly in my interest to obtain insurance, but at the same time I am aware that I am being unfair to the other policyholders in the scheme by making them pay for my apartment. This is why the principle of good faith is such a fundamental rule, consistently and rigorously upheld by the courts. This principle is a pre-condition for any insurance contract.

The second big issue is "anti-selection" or "adverse selection". Basically, the problem is this: what we tend to refer to as 'insurance' as if it were a single entity is actually just individual insurance companies competing with each other in the market place. The mutual insurance scheme administered by each individual insurance company does not cover the whole mortality table. The problem for individual companies is to know how far their own portfolio diverges from it. Companies which fail to fix the right price for the risks they underwrite will soon see their customers defecting to competitors who can offer to cover the same risk for a more reasonable premium. As a result, the former would soon be left without that section of the population which they need to balance out their portfolio. They would then have to raise their premiums, which would mean losing further customers. The company would then be left with nothing but future claims to look forward to and would, therefore, be doomed to go out of business. It is up to insurers to make sure that their portfolios are balanced and to avoid insuring people who know perfectly well that the risks they constitute exceed the premium they are being asked to pay. There are two main reasons why people take out insurance: one is because at some point in their lives they may have certain plans which life insurance will help them make come true, although they do not know exactly what might happen to them in the future. In this scenario, the people seeking insurance do not have any particular risk in mind.

However, insurance applications can be prompted by the sudden discovery of a risk, for example, as the result of a medical examination: this is tantamount to taking out the insurance immediately before putting in the claim. This is clearly the kind of situation where insurance becomes the most desirable, but also the most problematic, because in cases like this what motivates the insurance application is also what makes it difficult to be accepted, at least in normal circumstances. The law forbids taking out insurance for a risk which is certain to materialise.

The question is: are these two sets of demands (the requirements of collective ethics and those of the insurance business) compatible? Particularly when it comes to genetic testing?

Taking the English example, it is possible to give an affirmative answer. Here the key idea is "relevance" or, in French, "pertinence". This may be defined in terms of a number of rules: insurers must be entitled to protection against the risk of anti-selection that would arise if their customers were allowed to conceal facts that had a bearing on their insurance application. Hence the first rule: insurers are not allowed to require applicants to take a genetic test as a condition for taking out a policy, since the only issue from the insurer's point of view is having access to the results where a customer has already taken such a test for some other reason and knows the results.

Once this distinction is made, it leads on to a second set of rules: what type of genetic tests are insurers entitled to ask applicants about (i.e. whether they have taken such tests and whether they know the results) and for what type of insurance? This is where the idea of "relevance" comes into play on two fronts. First, there is the issue of whether the test is reliable for the type of insurance policy concerned. It is perfectly possible for a test to have diagnostic value that is "relevant" for medical purposes but to have no reliable predictive value, i.e., not to be "relevant" for insurance purposes. This is the case for virtually all the tests currently available. Second, consideration must be given to whether the information provided by a given test is relevant for assessing the risk in connection with a given guarantee. A test showing a twenty-year-old to be at a higher risk of developing a certain condition and dying when they reach the age of 80 is hardly relevant to assessing the risk of their dying in five years time.

The "relevance" criterion rules out blanket generalisations. Certain tests may well be relevant for one type of insurance, but not for another. Reasons, therefore, need to be given on a case-by-case basis, depending on the type of test, to determine whether or not the insurance company should be entitled to be told the result of a test already taken, although it cannot require a test to be taken in the first place. It is obvious that this delicate case-by-case approach is difficult to legislate for, since the law operates in terms of generalisations and fixed values. This is why the authorities in England set up an independent committee whose job it is to assess both the reliability of tests and their relevance to given types of insurance. This idea of "relevance" doubtless helps reconcile the ethical requirements (non-discrimination and access to insurance) with the requirements of the insurance market in areas such as life insurance. Banning insurance companies from having access to genetic information (which boils down to giving policyholders the right to lie when it comes to genetics) amounts to subsidising individuals so that they can get the insurance they need. This is effectively a way of introducing a welfare-based element into the private property sphere.

Legal developments in various European countries are now tending to move in this pragmatic direction. There has been a change in attitude since the beginning of the 90s. Laws in Belgium (1992) and Austria (1994) introduced bans, pure and simple, at a time when insurance companies in those countries would have been at a loss to know how to respond to genetics issues. The purpose was to forestall any subsequent slippery slope. Eight years on, we can see the situation in Britain: no legal ban, but a code of practice, overseen and monitored by the authorities, which allows for changes to be made as knowledge improves. This is reflected in the situation in France. In 1994 the French Parliament introduced strict rules as part of the legislation on bioethics. The Council of State, which the government has asked to evaluate the provisions, is proposing an approach that acknowledges both the tentative nature of what is currently known about genetics and the legitimacy of certain requirements of the insurance industry. The Council of State is, therefore, proposing the introduction of new distinctions.

There appears to be a move away from dogmatic, black-and-white thinking towards a more hands-on, subtle approach. An example of this is Article 28 of the Council of Europe's Convention of Oviedo, which reads as follows: "Parties to this Convention shall see to it that the fundamental questions raised by the developments of biology and medicine are the subject of appropriate public discussion in the light, in particular, of relevant medical, social, economic, ethical and legal implications, and that their possible application is made the subject of appropriate consultation." This is more conducive to an attitude that is open and sensitive to new developments rather than curtailing debate with rigid legislation.

ROUND TABLE DISCUSSION
(Following individual presentations)

Ms Lenoir (to Mr Ewald): Apparently there is a clear distinction between the world of work with its principle of solidarity and protection on one hand, and the world of insurance on the other. I speak here about life insurance in particular with its principle of mutual trust and confidence. There is no mention of the socialisation of the risks. We should not forget though that the complementary risk, which is covered by mutual scheme, is increasingly going to be the type of risk covered by private insurers. There will be a bridge built between private insurers and public insurers mutual schemes or public health services. This is the trend in all Member States. It has been included in Community legislation as Directives on insurance cover the mutual societies. This problem is not far from the issues that are being discussed here today.

Another point I would like to make is that it seems quite clear by now that there are some parties who wish to have preventive legislation, while there are others who are in favour of self-regulation which would be managed by public authority, but not by binding law. What are the reasons behind 'moratoriums' that the French companies have decided to create in contrast to their British counterparts?

Me Ewald: The reasons behind these moratoria are two-fold. Firstly, as far as an insurer is concerned, genetics constitute an additional complication; genetics do not make things simpler or easier in any way. If what we have heard is true, then we would have to change everything as regards our acceptance of risk because the processing of all this information would become almost impossible to manage. The insurer does not wish to have as much information as possible. The second reason is the one which you have recalled, namely that insurers fear that in the current situation it is far too early in the day to take any decision, apart from the case of the one or two specific tests of illness which we can test. I think that the British have asked for the recognition of seven tests covering a number of very rare elements.

Ms Nielsen: I would like to make three small comments. In the area of risk-selection, it would be a good thing for one company to make a more thorough gene testing to reduce their risk compared to the other companies. The second point is about regulation. It seems to be a case-by-case approach versus a formal legislation approach. However, the differences between the two are not as big as you might think. This is because in the formal legislation approach there must be room for a number of exceptions and board or committee may decide those exceptions. The third point we should address is how do the topics we have discussed so far cope with the biomedicine conventions we have heard about? Can insurance companies do that kind of genetic testing without being in direct confrontation with these conventions?

Mr Ewald: In the code of practice the British insurers undertook not to undercharge. The rule that they set themselves was that if an individual came to an insurance company and said I am better than the others so give me a better price, all the British insurance companies agreed to refuse such a request. The problem will be to try to look at the status of someone seeking insurance coverage being aware of the fact that their genetic risk is perhaps worse than that of others. That would seem to imply that we should have European legislation, because otherwise we would have distortion of competition.

Mr Winter: Obviously we have reached the consensus of excluding insurance and employment when it is claimed to exceed the testing-possibilities provided by the new genetics and genetic testing. This having been said, we also have genetic linkages in asking family history, so I am not so sure whether this grey zone we do have, whether this overlap can be 100% excluding genetic tests when we measure

things we have measured before with the conventional, traditional medicine. This is a task my Group in the Council of Europe does have and we hope to finish the Protocol by end of 2002.

Ms McLaren: I want to return to the question of employment. I think that Mr Kent and Mr Vogel are in complete agreement and that they regard genetic testing as a health-care issue that they do not want to see in the workplace setting. Mr Vogel is in favour of legislation, while Mr Kent argues that we at the moment do not know enough to form legislation. This, however, is more a difference of tactics, and not a difference of strategy. We have experience in the U.K of legislation in the field of assisted reproduction, and although that has been extremely useful, there is no doubt that it is inflexible and one sees that in a complex piece of legislation there are parts that would have been better to have be drafted differently. There are also the new developments, which have not been taken into account. I think that was in the back of Mr Kent's mind when he was recommending a government advisory committee rather than primary legislation.

Mr Vogel said that he would be in favour of getting rid of all genetic testing from the workplace with one or two exceptions. However, I did not understand what those exceptions were and I would be grateful if you could precise them.

Mr Vogel: I would like to start on the point of exceptions and then to move on to tactics and strategies. I cannot give you any precise examples of tests that could be used in the workplace. My point, however, is that I cannot say that today and for eternity there will be no justifiable use of genetic tests in the workplace. I believe that we have to see the exceptions from the following points of view. Firstly, we need to have a good look at the inevitable occupational exposure and see how that links in with genetic factors, that would be the basic premise and we would have to see how the two interact. Secondly, we would have to ensure that the workplace could not be changed in such a way as to afford level of protection. And thirdly, we would have to ensure that the test results have to make it quite clear that within a reasonable amount of time, this particular individual will develop certain pathology. If all of these factors were present in the test, we would have to see what social accompanied measures could be enacted to make the test acceptable. What I would like to avoid is a situation where the employer would decide exceptions on a purely discretionary basis. We have to have very clear law, very clear legislation, which will set out what the rules are and what the possible exceptions would be as we have in place areas of occupational health.

On the question on tactics and strategy I do not want to be polemical. Each approach is based on different considerations and may be discussed as such. But, let's take the best of our possible attentions to ensure that we have at least the first basis for perhaps future regulation. This is a European Committee so I think we have to reason on the basis of the instruments, which the European union has at its disposal. In the area of health and safety at work experience has taught us that the rules are enshrined within Directives while the Recommendations, on the contrary, are not applied in Member States or were applied some 30 years later. The fact that the European Commission in its own practice has not applied the non-binding texts such as Recommendation on AIDS test for example, demonstrates quite clearly that Recommendations are not the most appropriate instruments. I cannot speak for the national situation but I think that at the European level the best European instrument for prevention policy and for health and safety at work would be a Directive.

Ms Lenoir: Questions on codes of practice are at the heart of this debate. Such codes of practice work quite well in countries governed by common law, in other countries they do not function that well. This touches upon the question of how binding law interact with collective bargaining decision, what should be seen as an imperative rule, and what should be left to the social partner?

Mr Tambuyzer: I would like to highlight the fact that the statement that the area of genetic testing is developing very fast is both true and untrue. Currently in the United States genetic testing is clinically available for more than 300 diseases or conditions. We can say for most of those that they are diagnostic tests and should not be considered differently from the other diagnostic tests. There are additional 325 diseases and conditions for which tests are being developed. I think that most of them might be related to predictive testing .It is developing quickly, but we know from previous experiences that it takes time before a test is seen as valid. When we speak about control and regulation, I think that the first thing we need to do is to look at the clinical and analytical validity of a test, at what point does it become clinically valid? I plead for some control but I do agree with Mr Kent that flexibility is needed in this area because it is developing very fast.

Mr De Wachter: I would like to talk about the dilemma of the occupational physician in the workplace. This person is constantly caught between two types of loyalty: an employer hires him and he is supposed to protect and to promote the health and the benefits of the workers. The discussion today has hardly looked at the responsibility towards the employer. The French situation was nicely summarised by saying the physician gives the judgement if one is apt or inapt and there his responsibility stops. There is no dialogue between health care occupational physician and the employer. Mr Van Damme was speaking about negotiation, which is not the medical area. What does it mean when Professor Lebeer says that the physicians should give the proper genetic counselling? What are the content criteria for judging and negotiation? Is the one-to-one dialogue with the future employee considered as medical dialogue only?

What I would like to hear more clearly here is that there are not only two people involved. The physician has one additional person behind him, the employer, that he does not have to protect but there is an intention…That intention was taken into account in the scientific model and standardisation model mentioned today but yet the social and economic context is missing. Should we consider those values as well or continue speaking about a one-to-one relationship?

Mr Leeber (to Mr De Wachter): As I see it the occupational physician is in place to protect the health and the interests of employees. That is his primary task and I have stressed the fact that I believe that since the occupational physician is there to serve the interest of the employees, he or she should be able to benefit from full autonomy vis-à-vis the workers. I think that we have to look at the relationship between the physician and the employee without looking at his social background.

There are two main-trends emerging in occupational medicine today that are based on developments taking place in the public health sector. First, I think we might see more pre-employment tests, and of course the pretext of this might be that you would have to test more to protect health, but at least they do not have anything to do directly with the post to be occupied. Second, this might be seen in conjunction with a situation where occupational medicine is seen as social medicine rather than strictly clinical medicine. Mr Van Damme mentioned the whole idea of a code of practice which has been adopted by the International Association of Occupational Physicians, which defines the work being done by these doctors as something different from the type of clinical medicine practice of other physicians. This is very important and should be pointed out.

Mr Van Damme: What I meant by negotiation was that because occupational health physicians have the competence to judge the complex questions of exposure and susceptibility, and know the job-requirements, they are in a position to negotiate, or help the worker to decide which test to take. This is not scientific but protective approach. In most European Union Member states the role of the occupational health physician is already clearly defined by law.

The negotiation between employers and employees' representatives takes place in these countries at national level. In Belgium and in France the employees can even take the decision to get rid of occupational health physician if they do not have confidence in that person any more.

There are three rules that have to be applied regarding pre-employment testing, firstly, testing can only be done by the people who have the competence to do it, and these are the occupational health physicians. Testing should only be done within the spirit of protecting both health and employment. Secondly, other medical examinations with different objectives should not be done prior to employment. Finally, pre-employment examination should be the last step in the procedure of hiring a person. This way the workers are protected and I would very much welcome the strict regulation of pre-employment testing practices.

Mr Saint-Upéry: I agree entirely with Mr Leeber and Mr Van Damme as regards the relationship between occupational physician and employee It is true that the staff representatives may ask for an occupational health physician to be fired for various reasons. On the other hand it is possible for an employer to ask the termination of a contract of a an occupational health physician as long as the Trade Unions give their agreement This does provide guarantee over the independence of physician. From a legal point of view the occupational health physician is the superior of the employer. In France we made a proposal for the occupational health system, and that is that the occupational health physicians should get their salary, not from the state, but from a financial collective derived from contributions paid by the employer

I represent about 80% of occupational health physicians in France. Since 1993 we have been thinking about introducing genetic testing in the workplace. On the basis of our experience as physicians working in the field we are formally opposed to the use of genetic testing on a systematic basis. We think that genetic tests are quite different from other types of biological tests. This is because of the objectives of trying to detect pathologies. I think there is a fundamental difference because on some data, genetic tests violate the intimacy of the individual and may modify, not only that persons professional life, but also his or hers whole existence. This is not the case with other biological tests. As Mr Vogel pointed out we are subject to a substantial economic pressure from employers. They want us to use tests on HIV or drugs abuse for instance. But the pressure comes from laboratories manufacturing these tests as well.

In certain situations, however, we might accept certain tests, if implemented with the initiative of the occupational health physician, and only with the consent of the individual.

Ms Lenoir (to Mr Ewald): On the matter of insurance companies and medical consulting, especially regarding the medical secrecy, protection of privacy and confidentiality, it would be interesting to know how this is dealt with by the insurance companies? What kind of communication exists between doctors for instance? How does the medical adviser in insurance company maintain medical confidentiality vis-à-vis insurance company and his colleagues?

Mr Ewald: Basically, medical counsellors are advisers for the insurance companies, their salaries are paid by them, but their actual work is independent of the insurance companies administrative board. Medical advisors are consulted should it appear that there is a problem with risk-assessment. In such cases the medical advisor will carry out an examination and propose an insurance solution to the company. However, the medical advisor cannot reveal the medical reasons behind his or her proposal.

Patient Associations have asked for all medical information to be diverged only to insurance company's medical adviser in exceptional circumstances. In case of insurance for loans and banking, the insurance companies have delegations, which would enable a borrower to get his loan in just a few days time. This of course can make problems. The associations have feared that this creates a situation

of stigmatisation for those who send their medical questionnaires only to insurance company medical adviser. This would mean that we would have to arrive at a situation in which in all cases the medical questionnaire would have be kept separate from the application for loan and would then be sent on systematic basis to insurance companies medical adviser. If that would be the case then of course that might run a risk of lengthening the procedure quite considerably. Although the Patient associations make it very clear that in all cases there is virtually no exceptions that the dossier should be sent directly to insurance companies medical adviser.

Mr A. Francisco: I am specialist in occupational medicine and I work in the Commission's Health and Safety at Work Unit. I think it was a very good idea to invite an expert on the issue of insurance, because it is necessary to look at the parallels between genetic testing in the workplace and in insurance cases.

After Mr Ewalds presentation I got the impression that his view on the insurance situation is somewhat idealistic compared to my own experience, and perhaps other peoples experiences. I recently asked for insurance premium and I was quite surprised when the insurance company informed me that the contract was ready but that I had to pay an extra premium of some 80%…I argued this decision considering myself a fairly good insurance candidate. I do not suffer from any serious disease. The reason for the additional premium was that I had indicated in medical questionnaire that I had gone to a rather insignificant operation. However, the insurance medical adviser clarified this to me and solved the problem I my favour. If I wanted to change the insurance company for example it would not have been easy. There is the questionnaire in which you are expressively asked whether another company has refused your application or whether you have been asked to pay an additional premium. Thus one becomes a bit "suspect" candidate…

I find it rather difficult to establish a parallel between the world of insurance and the world of work. The predictive value of genetic testing is not absolutely accurate and I do not think that we can say that the genetic tests can be deterministic. I can understand that in world of work we try to prevent problems while in insurance sector it is not the case. It is the question of business and commercial interests. In European legislation we have legislation which aims to protect workers from point of view to exposure to certain risks. As Ms Levitt said the principle is to eliminate the risks not the workers. The insurance on the contrary can always exclude someone who constitutes a problem. One may be put on insurance company black list as a private citizen. Perhaps I am exaggerating but I think that we have to be aware of the fact that there are such fears among European citizens and that there are reasons for legitimate concern in this area.

However, as genetic testing is not yet in place so much, perhaps it is not now the best time to anticipate the problem. As Mr Vogel says we may plead for prohibition but at the same time leave the back door open to some exceptions. I do agree that such exceptions should not be decided by virtue of collective bargaining agreement. We should realise however that the situation is not yet clear and I think that the time is not right to us to move towards the legislation.

Mr Ewald (to Mr A. Fransisco): The situation you described occurred in one of the companies and does not call into question genetic tests as such. It could be interesting to analyse it in order to establish whether that situation in terms of genetic tests in the future should imply new rules and norms. The situation, which you encountered, is at the crossroad of two problems. First, subscribing to an insurance policy is based on the assumption of truth. This truth might be different from the truth that one had the perception of, and there can be major differences between a medical point of view and an objective risk-evaluation. Secondly, it is important to keep in mind that there is an insurance market and that insurance companies vary. One insurer will not necessarily take the same attitude as the other. It is the

question of portfolio: an insurance company can cover a certain range of risks and can take different attitudes from one case to another.

The present law says that utilisation of data relating to health for insurance or employment purposes must not constitute discrimination. If we have a look at the British situation and the counselling system that has been set up we can see that the objectivisation of the evaluation risk is something, which is intended to become general. The insurance evaluation risk should become the subject to public debate and should not be done only by insurance company's doctor. The feeling that you have been banished or excluded is due to the fact that for the moment no other forms of guarantees have been developed that could give you guarantee of access to a mortgage.

However, I do not think that we need any other legislation or principles but what is true is that the situation raising out of genetic tests makes it necessary to give to these principles effects which have not yet been formulated up to now.

Ms Gebhardt: As a member of the European Parliament I have very much sensed the demands for powerful legislation and this is the kind of actions which I am going to propose in discussion which I will be having in the future on this question.

As to the question of insurance and British situation mentioned by Mr Ewald, I would like to add that in the early 1990s the German insurance companies exerted considerable pressure on politicians precisely with the view to be able to use genetic tests for their insurance policies.

Now, I would like to turn to Mr Vogel: I think that Mr Ewald has given you a further powerful argument when he told us that, if you know something about your health-status you are obliged to divulge this information to the insurance company if you want to take a life insurance. So if you are obliged in one way or another to undergo genetic tests at work, and if as a result of that you come across a fact that you were unaware of, then you will be obliged to use this new fact in the context of your insurance policy. This is an entirely new point of view to me and I think that it is really going to require clarification.

Another point that I think needs to be further clarified is the question of confidentiality of the members of the family. A genetic test implies something that might be common to the whole family. One person of the family may want to know what his genetic problems are but another member of the same family may not want to know it at all. How can we solve this problem? This is also a crucial point of ethics that should be discussed furthermore.

Mr Mieth: There are two aspects that I would like to point out. First of all, if there is any individual interest on genetic testing in the workplace, I believe this interest will start earlier than the pre-employment situation. It will start on the question of qualification, before the individual decides in what field to work in or what subjects to study. Secondly, if these tests start earlier, the question of prediction becomes more important. There is a great gap between diagnosis, which is possible, and prediction, which is not possible. We therefore have to discuss what criteria we will accept for a good prediction, which is not only a scientific question. It is also embodied in social and ethical questions. We have to see what will be the ethical aspect of criteria of a good prediction i.e. the one that is applicable and can be accepted.

Mr Vogel: Mr Ewald referred to the possibility of introducing into the working relationship a few elements of the competitive relations that exist on the insurance market. From a historical point of view there have always been conflicts between the logic of insurance and that of health in the workplace. For instance, there was a systematic battle waged by privately based insurance companies to prevent the recognition of silicosis as occupational disease. The only country who recognised it in 1905 was South Africa. The western countries did it only in early sixties. What has to be clear is that in the context of the

relation at the workplace, the rules must be specific, and have to apply to insurance companies to the extent that they interact with those rules. Insurance companies have to submit to the common rules applying to the workplace. They should not try to import their rules to the work's sphere.
Mr Van Damme has raised another important point. I do agree with him when he says that trade unions have to establish absolutely clear-cut positions on the question of pre-employment tests.

Ms Tempel: I just wanted to underline the point that Ms Gebhardt made about the right not to know our genetic destiny. It is of crucial importance to define the margin of manoeuvre of which the principle of not wishing to know is enshrined.

Ms Sorsa: I think this has been an excellent debate, in which we have highlighted the different positions. There is, however, one point that we have not touched upon, namely research. We do need the possibility to do research in the area of genetic susceptibility, and we cannot forget that there is freedom of research as there is freedom of thought. This research should come to prevention of health conditions caused by occupational exposures and end up in the strength of evidence what genetic tests can and cannot reveal. This research, however, should be done in an open and transparent way, following the fundamental ethical principles.

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