

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

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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 Conventions¹ and Community directives² 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. 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 job³. Our considered opinion, therefore, is that decisions about genetic screening should never be left purely to agreement (between the worker, preventive services, employer).

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).

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).

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”.

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.

European round table on work-related genetic testing

The European Group on Ethics in Science and New Technologies (EEG) staged a round table on work-related genetic testing on 6 March 2000 as part of the groundwork for an EEG opinion to be published in October 2000. It was attended by EEG members, MEPs, representatives of international organizations (OECD, Council of Europe, WHO), and Commission officials.

The EEG was originally set up by the European Commission in 1991 as an advisory group on biotechnology ethics, assuming its present form in December 1997. It gives opinions when requested by the Community institutions or on its own initiative. It has twelve members and is chaired by Ms Noëlle Lenoir. To date, it has published 14 opinions.

The 6 March round table coincided with US President Clinton's announcement of a ban on genetic testing for government employees and future legislation for the private sector.

The panel discussions focussed on talks by:

Karel Van Damme: scientific aspects of genetic testing

Mairi Levitt: ethical aspects

Linda Nielsen: legal aspects

Guy Lebeer: sociological aspects

Alastair Kent: the views of patients' representatives

Laurent Vogel: the [European Trade Union Confederation viewpoint](#)

François Ewald: the view of insurance companies.

UNICE was invited but did not attend, presumably because the employers do not yet have a joint position on the issue except, of course, being opposed to any form of Directive.

There was a **general consensus that no form of currently available genetic test is relevant to workplace prevention**. They relate either to diseases unconnected with work (e.g., Huntington's chorea) or have only a very rough-and-ready predictive value (e.g., for most cancers). However, tests could well find their way onto the rapidly-expanding European market in the not-too-distant future and come into use (the only known one in Europe so far is in the British aviation industry). They are steadily spreading uncontrolled in the United States. The business-based health care insurance system is clearly a major factor here, aimed more at weeding out potential sick benefit claimants than preventing work-related sickness.

All the speakers agreed that these tests raise serious issues and that it would be dangerous to leave the market to develop unchecked.

The main differences were over:

What rules are needed? Who should set them? When?

What rules are needed?

We want them banned (possibly with genuinely exceptional, i.e., strictly defined, exceptions). Others favour essential criteria set according to the relevance of tests and a non-discrimination clause, but no general ban. Decisions in individual cases would be left to the professionals or even employers (the proposed scheme being that applied by insurance companies).

Danish legislation was also discussed. It treats genetic tests as another form of medical information and centres on the worker's disclosure of medical information to the employer.

Points about this legislation:

- it does not match up to the European model of prevention. There is no reference to preventive services, nor the link between medical information and collective prevention activities;
- there are 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 influence behaviour (drug-taking, drinking);
- it is not acceptable in most European countries where employers never get to see medical data, only what they may mean in terms of aptitude;
- it is based on the idea of informed consent, which not appropriate to employment relations.

Who should set the rules?

One possibility would be for professionals and/or joint industrial bodies to draw up codes of practice. The ETUC wants Community legislation because fundamental freedoms are at stake and prevention falls under Community powers.

When?

Some speakers wanted to wait and see. The ETUC says that the track record in other areas (denying jobs to HIV carriers) shows that action is needed now; the legislative rules can always be kept under review.