Ethical, legal, economic and social implications of human genetics

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The Temporary Committee on Human Genetics and Other New Technologies in Modern Medicine adopted the report by Francesco FIORI (EPP-ED, I) winding up its year-long work investigating the social, legal, ethical and economic implications of human genetics. The committee's basic premise was that freedom of research must be preserved but that the most important objective must always remain the public benefit of such research. The EU had a duty to encourage research into biotechnology and human genetics, as basic research could not be left entirely to the commercial world. The public authorities needed to lay down clear ground rules for any research in the field of biotechnology, whether carried out by the public or the private sector. As far as human genetics were concerned, the subsidiarity principle applied. However, the EU had powers in this area as a result of the measures it could adopt in the field of public health, freedom of establishment and freedom to provide services, workers' rights and research funding. The committee called on both national and EU lawmakers to influence developments in biotechnology and medicine through the way in which funding was allocated. It also said that a harmonised regulatory framework at European level was needed. The report also highlighted the thorny issue of the patentability of living human material, in connection with Directive 98/44/EC on the legal protection of biotechnological inventions. The committee argued that all living matter must be deemed to be non-patentable. The committee endorsed the priority assigned to genomics and biotechnology for health in the proposal for the 6th Framework Research Programme, provided no funding was allowed for research into human cloning, be it reproductive or therapeutic. Indeed, it called for a ban on human cloning to be introduced worldwide. It was also against the creation of embryos for research or for any purpose other than bringing about a pregnancy, and opposed any modification of the germ line of human beings and the creation of chimera and hybrids. However, the committee expressed unequivocal and unreserved support for work into adult stem cells. Member States were urged to consider ways of allowing surplus embryos to be adopted by sterile couples. However, no trade in human embryos, embryonic stem cells or ova and spermatozoa should be allowed in Europe, although it was acknowledged that both the destruction of such embryos and their use in research were controversial from an ethical viewpoint. The committee said that genetic tests carried out for predictive and diagnostic purposes should only be performed in order to detect possible serious hereditary diseases. It added that, whatever the future possibilities of new technology, it would be impossible to eliminate all illnesses and disabilities from the world, hence the need for ill and disabled people as well as their families to receive support from society. The report emphasised the need to provide personalised care using the new biotechnologies but also stressed the importance of continuing with research into the causes of illnesses, which may not always be genetic (e.g. hygiene and eating habits, smoking, etc.). The use of genetic data to make it more difficult to take out life assurance or health insurance might in the end create new social hierarchies. MEPs argued that insurance companies should not be entitled to be given information about genetic data of which a person applying for insurance was aware except where the amount of the insurance policy was extremely high and there was a suspicion that the applicant was acting on the basis of such prior knowledge. Employees should also have legal protection against any demand for genetic data. The committee called for a ban on any discrimination against employees on the basis of genetic criteria. An institutional framework was needed to ensure that access to the results of tests was allowed only for the purpose of genuine health protection and that such data remained confidential except where genetic fingerprints could be used to identify and apprehend criminals. In conclusion, the committee urged Parliament to continue looking at the issue of human genetics. It also felt that the Commission's European Ethics Group should be given proper interinstitutional status. Lastly, it called for an ongoing public debate and also for a forum to be set up, consisting of representatives from the European Parliament, the Commission and the Council, which would meet twice a year for the purpose of evaluating the impact of research investment.