Presidenza del Consiglio dei Ministri

ITALIAN NATIONAL BIOETHICS COMMITTEE

GENETIC TESTING AND INSURANCE

(20th October 2008)

abstract

"Genetic tests and insurance" triggered an in-depth international debate in recent years, hinging upon the assumption that genetic testing would shortly become a common practice in healthcare services. This anticipation proved to be only partially feasible, thus, the fears arising from the use of genetic tests on the insurance side outbalance the status quo, at least in Italy. However, a number of International Organizations and National Ethics Committees gather "advice" to put forward the opportunity of having a suitable shared discipline at a European level enabling, in the future, a broader use of genetic tests in the insurance field.

Following the aforementioned complex situation as well as its constant transformation, the National Bioethics Committee and the National Committee for Biosafety, Biotechnologies and Life Sciences (hereinafter "the Committees") contend that - better than a hasty and global legislative response - it would be relevant, at the moment, to seek a tangible and temporary shared solution attainable through non-legislative criteria that - performing on the basis of mutual trust and transparency within the European debate - on the one hand may prevent people genetically prone to certain diseases from being discriminated whenever underwriting an insurance policy, moreover - on the other hand - may guarantee protection to the insurance companies from the dangerous consequences deriving from anti-selection that risks to prejudice the supply of fair and adequate "prize money" for the large population concerned.

The Committees:

- While waiting to avail oneself of a broader scientific knowledge comparing to the one currently at hand;

- Provided that – under any circumstance- it shall not be appropriate to curb genetic testing diffusion for medical reasons fearing a negative outcome on the insurance side;

- Wishing to give its contribution embodied in an opinion as requested by the Steering Committee of the Council of Europe during the meeting held in Strasbourg on 3-4 December 2007, recommend:

- That a moratorium regime shall be made clear as to the use of genetic testing within the insurance field in those Countries that have not yet decided upon it, waiting for the end of the European debate;

- That insurance companies shall be provided with a self-regulation procedure, endorsed beforehand by the competent authorities and properly disseminated according to which:

- Companies commit themselves to guaranteeing the protection of personal data under the formalities enshrined in the regulations in force;

- Insurance companies do not demand that the client should undergo genetic testing in order to have an insurance granted.

Moreover, given the sole target residing upon joining a voluntary experimental programme of a pre-established time length, directed to the practical importance evaluation stemming from the introduction of a number of genetic data into the health form designed as a self-declaration, the aforesaid form being already working prior to the drawing up of the insurance contract, the

Committees recommend that, whether provided by the self-regulation procedure, it shall not be forbidden to the companies, when agreeing upon the insurance contract, to request and get hold of results relevant to diagnostic genetic tests previously taken by clients, thus, the latter being aware of such a step, for any insured amount.

Ultimately if, upon request of the client, the insured amount is to exceed a certain threshold (the extent to be set), it should be possible for companies, when drawing up the insurance contract, to request and get hold of results relevant to presymptomatic genetic tests previously taken by clients, the latter being aware of the result.

The Committees likewise recommend that also the Superior Institute of Health be entrusted with presymtomatic genetic test evaluation as well as its reliability and significance for insurance purposes.