Genetic Data and Labour Law*

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1. Introduction.

The subject concerning the use of genetic data for employment purposes[1122] is still confined, as far as concerns the Italian legal system, to a future perspective. Differently, with respect to other countries, particularly in the United States where the custom to submit workers or applicants to genetic tests is already well established, in Italy the same tests are not in use, also because of their costs. Eventually, this future perspective is not so distant, since we expect a broader diffusion of these practices because of the growing attention paid to this subject not only by the International and European observers, but also by the Italian observers.

It is obvious that the possible uses of the genetic tests for employment will depend on advances in medicine, as well as type and usefulness, significance and sensitivity of information obtained[1123]. Nonetheless, these data will be of great importance and of growing implication if, as we expect, thanks to the improvement of the gene mapping techniques, there will be an increasing number of illnesses of which it will be possible to establish not only a simple “predisposition” – a mere “future probability” – but also the “certitude” of a subject to contract them.

By now, thanks to the sequencing genome technique, it is possible to find out a number of diseases that a subject will certainly contract, and which are relevant also for employment purposes.

[1122] M. Aimo, Privacy, *libertà di espressione e rapporto di lavoro,* Jovene, Napoli, 2003, p. 87 ss.; K.A. Deyerle, *Genetic testing in the workplace: employer dream, employee nightmare. Legislative regulation in the United States and the Federal Republic of Germany,* in *Comparative Labour Law Journal*, 1997, p. 555; J.J. Fernàndez Domìnguez, *Pruebas genéticas en el derecho del tabajo,* Civitas, Madrid, 1999; S. Gevers, *Use of genetic data, employment and insurance: an international perspective,* in *Bioethics*, 1993, n. 2-3, p. 126; R. Guariniello, *Informazioni genetiche e riservatezza. Riflessioni sul mondo del lavoro,* in *Bioetica*, 2002, p. 671; F. Introna, *Lo screening genetico ed il giudizio di idoneità al lavoro,* in *Diritto e Società*, 1992, p. 29; G. Lyon-Caen, *Genetique et Droit du Travail,* in *Revue Internationale de Droit Économique*, 1993, n. 3, p. 68; V. Mele, G. Girlando, E. Sgreccia, *La diagnosi genetica sui lavoratori: recenti acquisizioni scientifiche, problematiche etiche ed etico-giuridiche*, in *Medicina e Morale*, 1990, p. 301; E. Rizzo, *Informazioni genetiche e riservatezza. Implicazioni in tema di contratti di assicurazione e di rapporti di lavoro,* in *Rassegna Amministrativa della Sanità,* 2001, n. 2, p. 122; A. Trojsi, *Sulla tutela dell’identità genetica del lavoratore,* in *Giornale di Diritto del Lavoro e di Relazioni Industriali*, 2008, p. 47; E. Vigo, *Dna: quale futuro per la privacy dei lavoratori dipendenti?,* in *Rivista Critica di Diritto del Lavoro*, 1994, p. 243; A.M. Zocchi Del Trecco, *Aids e informazioni sul patrimonio genetico,* in *Diritto e Pratica del Lavoro*, 1991, p. 1649.

[1123] G.F. Azzone, *Il contributo dei geni e della cultura allo sviluppo delle persone,* in *Bioetica*, 2004, p. 609 ss.; M. Bucchi, *Il Progetto Genoma e la scienza che cambia,* in *Il Mulino*, 2000, p. 1039; C. Casonato, *Diritto, diritti ed eugenetica: prime considerazioni su un discorso giuridico altamente problematico,* in *Humanitas*, 2004, n. 4, p. 841; C. Casonato (edited by), *Life, Technology and Law,* Second Forum for Transnational and Comparative Legal Dialogue (Levico Terme – Italy, June 9-10, 2006), Cedam, Padova, 2007; C. Casonato, C. Piciocchi (edited by), *Biodiritto in dialogo,* Cedam, Padova, 2006; R. Criscuoli, *La biomedicina ed il principio di identità genetica nel diritto europeo,* in *Nuove Autonomie*, 2002, p. 661; F. Di Marzio, *Manipolazioni genetiche della vita umana. Legittimazione e possibilità del discorso giuridico,* in *Rivista Critica di Diritto Privato,* 2003, p. 521; R. Elliott, *Identity and the ethics of gene therapy,* in *Bioethics*, 1993, p. 27; S. Filippi, *La clonazione umana e il diritto alla propria identità genetica,* in *Archivio Giuridico*, 2001, p. 509; G. Finocchiaro, *Possibilità di risposte terapeutiche alle conoscenze sul genoma umano e sui test genetici,* in *Bioetica*, 2002, p. 679; G. Gennari, *Identità genetica e diritti della persona,* in *Rivista Critica di Diritto Privato,* 2005, p. 623; J. Habermas, *Il futuro della natura umana. I rischi di una genetica liberale,* Einaudi, Torino, 2002; H. Jonas, *Technik, Medizin und Ethik - Zur Praxis des Prinzips Verantwortung*, Suhrkamp, Frankfurt a.M., 1987; B.A. Knoppers, *L’integrità del patrimonio genetico: diritto soggettivo o diritto dell’umanità?,* in *Politica del Diritto*, 1990, p. 341; P. Magnani, *Tutela del paziente e protezione dei dati genetici,* in *L’Arco di Giano*, 2005, n. 46, p. 167; N. Mucci, V. Romano-Spica, G. Ricciardi, S. Perticaroli, *Il sistema informativo GenScreen 1.0: uno strumento per l’informazione sui rischi genetici in ambito occupazionale,* in *www.bioigene.it/articoli_pdf/sistema_informativo_genscreen.pdf*, 2004; G. Pennings, *The right to privacy and access to information about one’s genetic origins,* in *Medicine and Law*, 2001, n. 20, p. 1; R. Prodomo (edited by), *Progressi biomedici tra pluralismo etico e regole giuridiche,* Giappichelli, Torino, 2005; G. Santaniello, *Ricerca genetica e tutela della persona,* Paper presented at the International Conference on «Social, psychological and legal implications of human genetics» (Rome, 21-22 March 2002), in *www.interlex.it/675/santaniello2.htm*, 2002; L. Trucco, *Introduzione allo studio dell’identità individuale nell’ordinamento costituzionale italiano,* Giappichelli, Torino, 2004, sp. pp. 53 ss. and 171 ss.; P. Vineis, *Test genetici e problemi bioetici,* in *Bioetica*, 2002, p. 690; D.C. Wertz, J.C. Fletcher, K. Berg, *Review of Ethical Issues in Medical Genetics,* in *www.who.int*, 2003.

These are the so-called "neurodegenerative monofactorial diseases", i.e. genetically determined diseases, such as the so-called "triplet-repeat pathologies"[1124] (the well-known Huntington's disease[1125], but also, for example, myotonic dystrophy[1126], spinocerebellar ataxias[1127] and Kennedy's disease[1128]). To this type of illnesses we can add the so-called "multifactorial" pathologies for which, actually, it is only possible to determine the predisposition of a subject to contract them (tumours, diabetes, schizophrenia, Alzheimer's disease, arterial hypertension, many cardiovascular diseases, etc.)[1129].

2. Fields of application and aims of genetic data use for employment purposes.

For a recognition of the fields of application of genetic data for employment purposes, we distinguish between three main sectors:

a) The sector of *labour relations*, where the processing of data is made by the employer or on his behalf: *during the* so-called *pre-recruitment phase*, with the aim of selecting applicants by identifying those not suited to a particular duty because of a declared illness or because of the presence of a particular risk to contract a disease, occupational or not, or because of the possible onset of a disablement status; and, *during the performance of the employment relationship*, in order to adopt decisions and measures for a better management of the employment staff (i.e., modification of duties, advancement, transfer, dismissal of the employee, protective measures for working environment)[1130]. The peculiarity of genetic diseases – with respect to the common pathologies – is that at the moment of recruitment it is possible (or rather frequent) that they have not developed yet and that, as a matter of fact, they will appear later, perhaps during the advanced phase of working life. Therefore, the employer verifies not the actual economic advantages, but the perspective convenience of recruiting or maintaining a worker in terms of costs and charges.

b) The sector of *labour market*: the subject of genetic data processing is already preminent during the phase which precedes pre-employment, and for its same reasons, i.e. during the phase of

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[1124] J. Shao, M.I. Diamond, *Polyglutamine diseases: emerging concepts in pathogenesis and therapy,* in *Human Molecular Genetics*, 2007, n. 2, p. 115.

[1125] F.O. Walker, *Huntington's disease,* in *Lancet*, 2007, n. 369, p. 218.

[1126] G. Meola, *Clinical and genetic heterogeneity in myotonic dystrophies,* in *Muscle Nerve*, 2000, n. 23, p. 1789; T.M. Wheeler, C.A. Thornton, *Myotonic dystrophy: RNA-mediated muscle disease,* in *Current Opinion in Neurology,* 2007, n. 20, p. 572.

[1127] A. Dürr, A. Brice, *Clinical and genetic aspects of spinocerebellar degeneration,* in *Current Opinion in Neurology*, 2000, n. 13, p. 407; L. Schöls, P. Bauer, T. Schmidt, T. Schulte, O. Riess, *Autosomal dominant cerebellar ataxias: clinical features, genetics, and pathogenesis,* in *Lancet Neurology*, 2004, n. 3, p. 291; B.W. Soong, H.L. Paulson, *Spinocerebellar ataxias: an update,* in *Current Opinion in Neurology*, 2007, n. 20, p. 438.

[1128] H. Adachi, M. Waza, M. Katsuno, F. Tanaka, M. Doyu, G. Sobue, *Pathogenesis and molecular targeted therapy of spinal and bulbar muscular atropy,* in *Neuropathology and Applied Neurobiology*, 2007, n. 33, p. 135.

[1129] M. Aimo, Privacy, cit., p. 90; A. Bompiani, *Genomica funzionale e proteomica: recenti sviluppi della ricerca nelle malattie poligeniche e considerazioni etiche,* in *Medicina e Morale*, 2003, p. 797; P. Borsellino, *Mappatura del genoma umano, protezione delle tracce genomiche e informazioni genetiche*, Paper presented at the Study Meeting held by the "Consiglio Superiore della Magistratura" on «Biologia, biotecnologia e diritto» (Rome, 8-10 November 2001), in *www.globius.org*, 2001; L.M. Bucci, M. Paganelli, A. Ventura, F. Ventura, R. Celesti, *Osservazioni etiche e implicazioni medico-legali in materia di "test genetici",* in *Medicina e Morale*, 2005, p. 799; A. Piazza, *Sul progetto genoma. Implicazioni etiche e responsabilità del genetista,* in *Bioetica*, 2002, p. 651; M. Pierotti, *La diagnosi di predisposizioni o suscettibilità genetiche all'insorgenza dei tumori,* in *Bioetica*, 2002, p. 659. In particular, on the relationship between genetic predisposition and the worker's exposure to carcinogenic agents, see A. Asmundo, D. Sapienza, G. Spatari, *Aspetti etici e di liceità dell'applicazione degli screening genetici in ambito occupazionale,* in *Giornale Italiano di Medicina del Lavoro ed Ergonomia,* 2006, suppl. al n. 3.

[1130] V. D'Antonio, *I dati genetici,* in F. Cardarelli, S. Sica, V. Zeno-Zencovich (edited by), *Il codice dei dati personali. Temi e problemi,* Giuffrè, Milano, 2004, p. 387 ss.

research and selection of personnel, particularly when these procedures are adopted by private agencies.

c) The sector of *social security*, in which emerge the same topics as those relating to genetic data for insurance domain. In this respect we have to disinguish between:

1) public (compulsory) social security systems for *accidents at work and occupational diseases, and disablement*, for which the genetic features of a subject may substantially affect the contribution obligations, and whose amount could be related to the probability evaluation and severity of the disease, and to the predictable degree of disability and its presumable length (permanence or temporariness of the cause which reduces the physical or psychological abilities);

2) public (compulsory) social security systems for *old-age retirement*, where genetic data may affect above all and even more than the contributive obligations, the quantification of the social benefits, through the estimate of proportionality of social benefits with respect to the expected lifetime (which is of inferior amount for subjects having lesser possibilities of getting a disease and, therefore, with a superior expectation of lifetime);

3) finally, the area of *integrative social security*, in which the danger of diversification and personalization of the premium and benefits in accordance to risk are even more affected on behalf of its voluntary, optional and supplementary nature, and which is still based on private-oriented attitudes.

d) Furthermore, it should not be forgotten that, in all the above mentioned sectors, genetic data of the employee’s relatives too may acquire relevance, since the same employee (or applicant) benefits facilities (i.e. permissions and leaves, social security fees, several types of assistance, etc.) relating to his or her relative’s health.

3. “Threats” and “Opportunities” in using genetic information.

The subject of the use of genetic data for employment purposes, commonly focuses more on the threats rather than on the opportunities it involves[1131].

The implied *threat* is that of *genetic discrimination*: i.e. unjustified disparity in the treatment of workers, based on genetic features[1132].

[1131] F.M. Cirillo, *La progressiva conoscenza del genoma umano: tutela della persona e problemi giuridici connessi con la protezione dei dati genetici,* in *Giurisprudenza Italiana*, 2002, p. 2209.

[1132] S. Alvarez Gonzalez, *Derechos fundamentals y proteccion de datos geneticos,* Dykinson, 2007; C. Casonato, *La discriminazione genetica: una nuova frontiera nei diritti dell’uomo?,* in *I diritti fondamentali in Europa,* XV Biennal Colloquium (Messina-Taormina, 31 May – 2 June 2001), Giuffrè, Milano, 2002, p. 641; G. De Simone, *Dai principi alle regole. Eguaglianza e divieti di discriminazione nella disciplina dei rapporti di lavoro,* Giappichelli, Torino, 2001, p. 83; F. Di Ciommo, *La privacy sanitaria,* in R. Pardolesi (edited by), *Diritto alla riservatezza e circolazione dei dati personali,* Giuffrè, Milano, 2003, II, p. 295 ss.; A. Guarneri, *Identità genetica e* privacy doctrine *(il modello statunitense),* in *La Nuova Giurisprudenza Civile Commentata*, 2007, suppl. al n. 4, p. 37; S. Rodotà, *Tecnologie e diritti,* il Mulino, Bologna, 1995, pp. 119-120 e 202; S. Rodotà, *Intervista su privacy e libertà,* made by P. Conti, Laterza, Roma-Bari, 2005, p. 126 ss.; S. Rodotà, *La vita e le regole. Tra diritto e non diritto,* Feltrinelli, Milano, 2007, sp. p. 196 ss.; G. Santaniello, C. Filippi, *Dati genetici, genoma e privacy,* in A. Loiodice, G. Santaniello (edited by), *La tutela della riservatezza,* Cedam, Padova, 2000, p. 542; N. Smith, *The right to genetic privacy? Are we unlocking the secrets of the human genome only to risk insurance and employment discrimination?,* in *Utah Law Review*, 2000, p. 705; M.L. Suarez Espino, *El Derecho a la Intimidad Genética,* Marcial Pons, 2008.

Actually, thanks to genetic data, the morphology of discrimination has changed. It presents, as a matter of fact, some totally new characteristics, which are not comparable to other causes of discrimination at work (sex and sexual orientation, race and ethnic origins, language, personal beliefs and opinions, age), even with respect to the more frequent forms of discrimination based on health conditions (seropositivity and AIDS, drug addiction and alcoholism, handicap)[1133]. In effect, for the so-called "traditional" forms of discrimination, the threat is determined by the belonging to a certain "category" or group (i.e. women, non-EU citizens, homosexuals, sieropositives, drug-addicts, alcoholists, handicap, etc.). The identification of a subject is easier if he belongs to a threatened "category". On the contrary, it is not possible to determine a "category" of subjects who risk to be discriminated because of certain genetic features, since it is not possible to define groups to discriminate. It is, on the contrary, a discrimination based on "personal and individual conditions", varying from subject to subject, and from case to case. Therefore, it is very complicated trying to identify possible or even actual discrimination tendencies. So, everyone can be potentially subject to a possible or actual discrimination, because of the countless various reasons connected to the extreme variability and complexity of genetic makeup. Obviously, it is absolutely not possible to distinguish between "good" and "bad" human beings for reasons of genetic differences. On the contrary, it may be possible that a subject – having certain genetic features or, even, having the same genetic features – is considered as suited in certain contexts, or fit for the execution of certain tasks, and is then discriminated in other contexts.

Nonetheless, in certain contexts, genetic discrimination can combine with other discriminating factors, such as those relating to ethnical origins. When certain genetic features are common to a number of subjects and when their diffusion is characterized by uniformity and extension, i.e. features belonging to a same territory or to a same race or biologic family. In this case, genetic discrimination can be assimilated to a "category" based discrimination, involving threats of stigmatization. From this point of view, the individual dimension is backed up by the collective dimension, even if in the same period a multiethnic and multicultural society is gaining ground[1134].

Differently with respect to other forms of discrimination, genetic discrimination is not based on the subject's "actual" status, already embodied and concrete at the moment of discrimination (i.e. being affected by a determined disease or impairment); rather, it is based on a purely "potential" condition, whose concretization remains uncertain.

Genetic discrimination has rather uncertain boundaries which are difficult to determine, particularly in employment. Therefore, it is surely more difficult to prevent discrimination with the traditional mechanisms of protection (in particular, gender protection), even if we try to adapt these mechanisms to a model of reference.

The *opportunities* of genetic assessment are, on the contrary, represented by the availability of another instrument for the *protection of health and safety* at work. They allow the adoption of targeted measures and behaviours aimed at limiting as much as possible the risk of onset of a

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[1133] On the discriminations at work see the latest, M. BARBERA (edited by), *Il nuovo diritto antidiscriminatorio. Il quadro comunitario e nazionale,* Giuffrè, Milano, 2007; S. BORELLI, *Principi di non discriminazione e frammentazione del lavoro,* Giappichelli, Torino, 2007; G. DE SIMONE, *Dai principi,* cit.; D. IZZI, *Eguaglianza e differenze nei rapporti di lavoro. Il diritto antidiscriminatorio tra genere e fattori di rischio emergenti,* Jovene, Napoli, 2005.

[1134] L. CHIEFFI (edited by), *Bioetica e diritti dell'uomo,* Paravia, Torino, 2000; L. CHIEFFI (edited by), *Il multiculturalismo nel dibattito bioetico,* Giappichelli, Torino, 2005.

certain disease for which a subject has a predisposition, when the pathology has connections to the work environment or to the materials used at work. Furthermore, they can be of help since they facilitate the *selection of a “worker suited for a particular task”*.

Because of the characteristics of these data it is, therefore, very difficult and delicate trying to distinguish between *legitimate assessment of physical suitability* (or not), even *protection of workers’ health* and, on the contrary, *forbidden discrimination*.

4. International and EU sources concerning the processing of genetic data for employment purposes.

The approach to this subject is mainly concerned with the threats connected to genetic tests, as confirmed by the prohibition of discrimination based on genetic features practically contained in the most important international and European sources [Art. 6, United Nations Educational, Scientific and Cultural Organization (UNESCO) Universal Declaration on the Human Genome and Human Rights, adopted on 11 November 1997; Art. 7, UNESCO International Declaration on Human Genetic Data, adopted on 16 October 2003; Point 5, Hugo Ethics Committee Statement of December 2002, on «Human Genomic Databases»; Articles 1 and 11, Convention of the Council of Europe (COE) on Human Rights and Biomedicine, adopted in Oviedo on 4 April 1997; Art. 21, Charter of Fundamental Rights of the European Union, proclaimed at Nice on 7 December 2000[1135]][1136].

As shown by the relevance given by the international sources, the subject concerning genetic data in employment is particularly important, together with the subject concerning health and life insurances with whom it is often put together because of their affinity[1137]. The concern is so high that the documents that specifically approach this profile are rigidly delimited, sometimes strictly closed, inspired by a prohibitionist attitude towards the processing of genetic data for employment purposes, especially if these are the results of “genetic screenings” on workers. Whereas, it is possible to notice a broader opening towards the so-called “genetic monitoring”[1138].

It suffices to mention in this respect international sources, such as: the International Labour Organization (ILO) Code of Practice on «Protection of Workers’ Personal Data» of 1997 (Par. 6.12), the ILO «Technical and Ethical Guidelines for Workers’ Health Surveillance» of 1998 (Par. 3.20), and the ILO Second Global Report on «Equality at Work: Tackling the Challenges», drawn up on

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[1135] R. Bifulco, *Dignità umana e integrità genetica nella carta dei diritti fondamentali dell’Unione europea,* in *Bioetica*, 2003, p. 443 ss. The same concern is at the basis of the Organization for Economic Co-operation and Development (OECD) «Guidelines for Quality Assurance in Molecular Genetic Testing», adopted on 10 May 2007; about this inquiry see also the OECD Report, of October 2007, on «Genetic Testing: a Survey of Quality Assurance and Proficiency Standards». See also E. Ronchi, D. Harper, A. Taylor, A.G. Haslberger, *Genetic Testing: Policy Issues for the New Millennium,* in *Community Genetics,* 2000, n. 3, p. 161.

[1136] G. Santaniello, C. Filippi, *Dati genetici,* cit.

[1137] S. Landini, *Assicurazioni sanitarie e privacy genetica,* in *Diritto Pubblico*, 2003, p. 219; S. Rodotà, *La vita,* cit., p. 193. For a more detailed recognition of the international and EU sources concerning this subject, please admit reference to A. Trojsi, *Sulla tutela,* cit.

[1138] On the various types of genetic tests, see A. Pizzoferrato, *Brevetto per invenzione e biotecnologie,* Cedam, Padova, 2002, p. 64 ss.; D. Shapiro, *Report on Genetic Screening and Testing,* in *www.who.int*, 1994.

10 May 2007; the UNESCO International Declaration on Human Genetic Data, adopted on 16 October 2003 [Art. 14(b)]; the Resolution 2004/9 of the United Nations Economic and Social Council, adopted on 21 July 2004, on «Genetic Privacy and Non-discrimination» (Point 5); the Statement of World Health Organization (WHO) Expert Advisory Group on «Ethical Issues in Medical Genetics» (adopted on 1998); the Report by the WHO Advisory Committee on Health Research, drawn up on 2002, on «Genomics and World Health», which has inspired the World Health Assembly Resolution WHA57.13 of 22 May 2004, this too about «Genomics and World Health») (Par. 8.3.2); and the Report of WHO Expert Advisory Group on «Review of Ethical Issues in Medical Genetics», drawn up on 2003 (Part II, Par. 5.4, 5.5, 7.3, 7.4 and 8.2.6; Table 3, Point 4; Table 6, Point 5; Table 7, Point 9; Table 12, Point 6)[1139].

Equally strict are the European sources, and in particular, as far as concerns the *Council of Europe*: the already mentioned Oviedo Convention of 1997 [Articles 12 and 26(1)][1140], the Recommendation n. R(92)3 of the COE Committee of Ministers to Member States on Genetic Testing and Screening for Health Care Purposes, adopted on 10 February 1992 [Par. 6(a,b)] and the Recommendation n. R(97)5 of the COE Committee of Ministers to Member States on the Protection of Medical Data, adopted on 13 February 1997 (Par. 4.7, 4.8, 4.9, 5.4 and 6.2)[1141]. Whereas from the *European Union* there are: the European Parliament Resolution on «The Ethical and Legal Problems of Genetic Engineering», adopted on 16 March 1989 (from Point 13 to 18); the European Parliament Resolution on «The Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine», adopted on 20 September 1996 (Point 6); and the European Parliament Resolution on «Respect for Human Rights in the European Union», adopted on 16 March 2000 (Point 64); the Communication from the European Commission, adopted on 27 August 2001, that launched the «First Stage Consultation of Social Partners on the

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[1139] See also: the Report by the WHO Secretariat on «Cloning in Human Health», drawn up on 1 April 1999 (Art. 8); the Report by the WHO Secretariat on «Control of Genetic Diseases», drawn up on 21 April 2005 (Par. 14); and the WHO Report, drawn up on 2006, on «Medical Genetic Services in Developing Countries. The Etical, Legal and Social Implications of Genetic Testing and Screening » [Par. 1, 2.1, 4.3.4, 4.4, 5 e 5.2(xv); Box 5, Point 2.1(j)]; the «International Ethical Guidelines for Biomedical Research Involving Human Subjects», prepared in 2002 by the Council for International Organizations of Medical Sciences (CIOMS) in collaboration with the WHO (Guideline n. 5, Point 17); the Hugo Ethics Committee Statement of February 1998, on «Dna Sampling: control and access»; the World Medical Association (WMA) Declaration of Helsinki on «Ethical Principles for Medical Research involving Human Subjects», adopted on June 1964 and more than once amended (above all, Par. 21); the WMA «Proposed International Guidelines on Ethical Issues in Medical Genetics and Genetic Services», adopted on 1997; and the WMA Statement on Genetics and Medicine, adopted on 2005 (Par. 19); finally, the «International Code of Ethics for Occupational Health Professionals», adopted on March 2002 by the International Commission on Occupational Health (ICOH) (Par. 12). See also, G. BERLINGUER, L. DE CASTRO, *Report of the IBC on the Possibility of Elaborating a Universal Instrument on Bioethics,* in *www.who.int*, 2003; S. RUMBALL, A. MCCALL SMITH, *Human Genetic Data: Preliminary Study by the IBC on its Collection, Processing, Storage and Use,* in *www.who.int*, 2002.

[1140] A. LORETI-BEGHE, *Normativa internazionale e ricerca biomedica. Conquiste attuali e prospettive future,* in *www.academiavita.org.*, 2001; C. PICIOCCHI, *La Convenzione di Oviedo sui diritti dell'uomo e la biomedicina: verso una bioetica europea?,* in *Diritto Pubblico Comparato ed Europeo*, 2001, III, p. 1301; S. RODOTÀ, *La vita,* cit., p. 175 ss.; R. SAPIENZA, *La convenzione europea sui diritti dell'uomo e la biomedicina,* in *Rivista di Diritto Internazionale*, 1998, p. 457; E. SGRECCIA, *La Convenzione sui diritti dell'uomo e la biomedicina,* in *Medicina e Morale*, 1997, p. 9.

[1141] See also the Recommendation of the COE Parliamentary Assembly n. 1512 of 25 April 2001, on «Protection of the Human Genome by the Council of Europe» (Par. 8); the Report by the COE Committee of Experts Health Department on «Medical Examinations preceding Employment and/or Private Insurance: a Proposal for European Guidelines», drawn up on 1996 (Par. 2, 5, 5.2, 5.3 e 6); and the Draft Explanatory Report to the Additional Protocol to the Convention on Human Rights and Biomedicine, concerning «Human Genetics», drawn up on 27 October 1997 by the Working Party on Human Genetics of the COE Steering Committee on Bioethics (CDBI) (Chapter II, Par. I).

Protection of Workers’ Personal Data» (Par. 4), and the Decision of the European Commission, adopted on 31 October 2002, that launched the «Second Stage Consultation of Social Partners on the Protection of Workers’ Personal Data» [Par. 3 and 4(b,g)][1142]; the Opinion of the European Group on Ethics in Science and New Technologies to the European Commission, n. 18 of 28 July 2003, on «Ethical Aspects of Genetic Testing in the Workplace»[1143]; and also the «Working Document on Genetic Data» adopted on 17 March 2004 by the EU Article 29 Data Protection Working Party (above all, Par. IV and V)[1144].

5. The Italian sources. The General Authorization for the Processing of Genetic Data of 22 February 2007.

In conformity with the indications given by the international and EU sources, the Italian legal system too seems to be mainly concerned with the risk of discrimination involved by the possible usefulness of genetic tests for employment. This concern is evident in the substantial prohibition referred to the use of genetic tests for employment purposes (except for extraordinary and definite cases), stated by the “Garante per la protezione dei dati personali” [i.e. the Italian data protection supervisory Authority, hereinafter referred to as “Garante”] in the General Authorization for the Processing of Genetic Data, adopted on 22 February 2007 – which is, in Italy, the sole source of regulation concerning the processing of genetic data, further to the special delegation contained in Art. 90 of the Legislative Decree n. 196 of 30 June 2003 (the Italian «Personal Data Protection Code»)[1145] – probably because of the particular delicacy of the existential values involved, and because of the absence in Italy of a specific legislative regulation on the use of genetic

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[1142] About this argument, see M. FREEDLAND, *Data Protection and Employment in the European Union. An Analytical Study of the Law and Practice of Data Protection and the Employment Relationship in the EU and its Member States,* in *www.europa.eu.int*, 1999; S. SIMITIS, *Reconsidering the premises of labour law: prolegomena to an eu-regulation on the protection of the employees’ personal data,* in *Scritti in onore di Gino Giugni,* Cacucci, Bari, 1999, II, p. 1581. See also, A. BELLAVISTA, *La protezione dei dati personali nel rapporto di lavoro dopo il codice della* privacy, in *Studi in onore di Giorgio Ghezzi,* Cedam, Padova, 2005, I, p. 319 ss. The European Commission has made further interventions on this matter, such as: the Recommendations of the European Society of Human Genetics of November 2000, on «Genetic Information and Testing in Insurance and Employment: Technical, Social and Ethical Issues», which is part of a *BIOTECH* program financed by the Commission (from Point 1 to 5) (about this document, see B. GODARD, S. RAEBURN, M. PEMBREY, M. BOBROW, P. FARNDON, S. AYMÉ, *Genetic information and testing in insurance and employment: technical, social and ethical issues,* in *European Journal of Human Genetics*, 2003, n. 11, suppl. 2, p. 123); the European Commission Study of 2002, on «Genetic Testing: Patients’ Rights, Insurance and Employment. A Survey of Regulations in the European Union»; finally, the «25 Recommendations on the Etical, Legal and Social Implications of Genetic Testing», adopted on 2004 by the EC Expert Group [Recommendation n. 11(a, b, c)] (on this matter, see S. GAINOTTI, A.G. SPAGNOLO, *Test genetici: a che punto siamo in Europa? A margine del Rapporto e delle Raccomandazioni della Commissione europea sugli aspetti etici, giuridici e sociali dei test genetici,* in *Medicina e Morale*, 2004, p. 737).

[1143] V. D’ANTONIO, *I dati genetici*, cit., p. 388 ss.; S. NIGER, *Le nuove dimensioni della privacy: dal diritto alla riservatezza alla protezione dei dati personali,* Cedam, Padova, 2006, p. 195. The Report from the Commission to the European Parliament, the Council, the Committee of the Regions and the European Economic and Social Committee of 29 June 2005, on «Life Sciences and Biotechnology – A Strategy for Europe. Third Progress Report and Future Orientations» [COM(2005)286], has confirmed, among the future priority actions concerning genetic tests, that it will promote an initiative for the protection of personal data of the employees at work, taking into account the Opinion n. 18/2003 of the European Group on Ethics in Science and New Technologies (Par. 3.4.2).

[1144] A. BELLAVISTA, *La protezione,* cit., p. 326; F. MASCHIO, *Il trattamento dei dati sanitari. Regole generali e particolari trattamenti per finalità di rilevante interesse pubblico,* in G. SANTANIELLO (edited by), *La protezione dei dati personali,* Cedam, Padova, 2005, p. 502.

[1145] R. ACCIAI, *I trattamenti in ambito sanitario,* in R. ACCIAI (edited by), *Il diritto alla protezione dei dati personali. La disciplina sulla privacy alla luce del nuovo Codice,* Maggioli, Rimini, 2004, p. 517 ss.; F. CAGGIA, *Il trattamento dei dati sulla salute, con particolare riferimento all’ambito sanitario,* in V. CUFFARO, R. D’ORAZIO, V. RICCIUTO (edited by), *Il codice del trattamento dei dati personali,* Giappichelli, Torino, 2007, p. 437 ss.; V. D’ANTONIO, *I dati genetici,* cit., p. 355 ss.; R. DE FRANCO, *Sub art. 90,* in C.M. BIANCA, F.D. BUSNELLI (edited by), *La protezione dei dati personali. Commentario al D.Lgs. 30 giugno 2003, n. 196* («*Codice della* privacy»*),* Cedam, Padova, 2007, II, data for employment purposes, and differently with respect to other countries such as the United States, Austria, Finland, Swiss Confederation, Sweden, France, Portugal, the Netherlands, Greece, Denmark and Esthonia[1146].

As for employment, with the aim of health protection, the Authorization is granted only to health care practitioners (Point 2) and «exclusively for the purpose of allowing the authorised entities to fulfil specific obligations and/or ensure that such obligations are fulfilled, or to discharge specific tasks set out in Community legislation, laws and/or regulations with particular regard to *prevention of occupational diseases*, and *rehabilitation from physical and mental disability and/or impairment*, pursuant to the law». In these cases, «the processing operations may also concern the filling out of health records, certifications and other health care documents». The Authorization is also granted if the processing of genetic data is «indispensable to fulfil specific obligations or ensure that specific obligations are fulfilled, or to discharge specific tasks as set out expressly in Community instruments, laws and/or regulations applying to *social security and welfare*, *occupational and/or population safety and hygiene*, also without the data subject's consent, in compliance with the limitations laid down in the Garante's General Authorization for the processing of sensitive data in the employment context (n. 1/2008, of 19 June 2008) and without prejudice to the provisions contained in the code of practice referred to in Art. 111 of the Legislative Decree n. 196/2003» (reference is made to the «Code of conduct and professional practice by public and private entities for the processing of personal data for social security purposes or in connection with management of employer-employee relationships», by now not adopted yet); in these cases, «the processing may also concern the information related to medical history and/or the data subject's family members» (Point 3).

Since genetic data may be processed only for the purposes and by the subjects mentioned by the Authorization (Point 6), for all other cases we are obliged to deduce the prohibition to use data (in effect, because of the application of the general statement in Art. 11(2), of the Legislative Decree n. 196/2003). In particular, as far as concerns the employment sector, among the "whereas", the same Authorization states that «any other processing operations concerning genetic data that are not referred to herein shall be regarded as unlawful, except for those mentioned above, including employers' activities aimed at establishing employees' and/or job candidates' professional eligibility, irrespective of whether such activities are grounded on the data subjects' consent».

Moreover, the same concern for the discriminatory potentialities of genetic tests for employment purposes had already been underlined in the Agreement signed by the Italian Minister of Health and the Permanent Conference for the relationships between State, Regions and autonomous Provinces, of 15 July 2004, and in particular in the Document containing the «Guidelines for medical genetics activities» (Annex A, Par. 4.1); and also in the Reports of the National Committe for

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p. 1346; A. Parisi, *Sub art. 90,* in S. Sica, P. Stanzione (diretto da), *La nuova disciplina della privacy. Commento al d.lgs. 30 giugno 2003, n. 196,* Zanichelli, Bologna, 2004, p. 385; O. Pellegrini, *Dati genetici,* in G.P. Cirillo (edited by), *Il codice sulla protezione dei dati personali,* Giuffrè, Milano, 2004, p. 357; G. Santaniello, *Genoma: le leggi che tutelano i dati ci sono,* in *Ragiusan*, 2000, n. 195, p. 458.

[1146] K.A. Deyerle, *Genetic testing,* cit.; B. Godard, S. Raeburn, M. Pembrey, M. Bobrow, P. Farndon, S. Aymé, *Genetic information,* cit.; F. Hendrickx, *Protection of workers' personal data in the European Union: general issues and sensitive data,* in *www.europa.eu.int*, 2002, p. 62 ss.; R. Lattanzi, *Il trattamento dei dati genetici,* in C. Bresciani (edited by), *Genetica e medicina predittiva: verso un nuovo modello di disciplina,* Giuffrè, Milano, 2000, p. 297; L.M. Franciosi, *Identità genetica e ricerca di forme alternative di tutela nell'esperienza statunitense,* in *La Nuova Giurisprudenza Civile Commentata,* 2007, suppl. al n. 4, p. 43; A. Guarneri, *Identità genetica,* cit.

Biosecurity and Biotechnology redacted for the Italian Superior Institute of Healthcare of 19 May 1998, containing the «Guidelines for genetic tests» (Par. 2.3.1, 2.3.4, 6.1, 6.1.2, 6.1.3, 6.3, 6.5 and 8), and of 19 April 2006, containing the «Guidelines for the certification of bio-banks» (Par. 5.1); finally, in the Opinion of the National Committee of Bioethics, of 19 November 1999, about «Bioethical orientations regarding genetic tests» (Par. 2, 8, 9 and 13).

6. Enforceability to the processing of genetic data of the principles and rules stated by the Italian labour law regarding the control of workers' health.

In effect, the Italian legal system has not a specific legal regulation with regard to the processing of genetic data for employment purposes.

Nonetheless, it is necessary to verify whether it is possible to enforce principles and rules already present within labour law, to genetic data. Before examining the general rules concerning the processing of personal data, it is necessary to refer with priority to the labour law system, since according to the principle of *lex specialis*, the last one – being in fact a "special regulation" – prevails on the general rules.

This subject is part of a broader argument about the limits of lawfulness in the use of information about workers' health conditions. In examining the regulations, it is possible to demonstrate that in the Italian legal system, even in absence of a specific regulation, the processing of genetic data for employment purposes is not at all lacking protection, since it is possible to refer to principles and rules, stated in general, for the protection of workers' health.

With regard to the category of workers' health data – undoubtedly one of the most delicate – the criterion of "relevance" of the workers' data aimed at the evaluation of his or her professional aptitude, fulfilment of work obligations and management of labour relations, considered as a condition of legitimacy for data processing – as expressed by Art. 8 St.lav.[1147] – has a particularly strict and defensive enforcement. The law shows a tendency to "legal predetermination", that can be considered as definite, towards all workers' health data considered as "relevant" for employment purposes, and therefore object of knowledge and processing for employment purposes, with the subsequent prohibition, sometimes expressed, but often implicit, of processing any other information whose use is not allowed by the legislator. Differently from the general laws in force concerning all other information about the worker, in this case the law directly assesses, case by case, the "relevance" of information concerning the worker's health, and its limits.

a) Following the above outlined subdivision in three sectors, with regard to the possible uses of data for employment purposes, we are going to begin with the sector of *labour relations*. At this point, it is necessary to underline that data processing can assume two forms: the exercise of a "power" by the employer, or the fulfilment of an "obligation" by the employer.

As far as concerns the employer's *power* to control workers' health conditions, the main rule of reference is Art. 5 St.lav.[1148]: from which it can be deduced that the sole information which is

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[1147] A. Trojsi, *Sfera privata del lavoratore e contratto di lavoro (artt. 5, 8 e 26 St.lav.),* in *Quaderni di Diritto del Lavoro e delle Relazioni Industriali*, 2000, n. 24, p. 196; A. Trojsi, *Statuto dei lavori e protezione della sfera privata del lavoratore,* in *Democrazia e Diritto*, 2004, n. 3-4, p. 54.

[1148] A. Trojsi, *Sfera privata,* cit., p. 216 ss.

"relevant" to the employer, either during the pre-recruitment phase, either during the performance of the employment relationship, is his or her "physical and psychological fitness for work" (eventually, "infirmity because of illness or accident" of the employee). This information can be verified only by public physicians (never by the employer directly, nor by his appointed physician), who, subsequently, have the exclusive right – i.e. without involving the employer who can only decide whether and when to submit the employee to medical control – to choose the necessary sanitary controls. Anyway, these controls shall be limited to those strictly necessary to assess the fitness for work, meant as the fitness for specific duties that the worker is concretely going to perform or is actually performing (not in the abstract). Furthermore, physicians can communicate only their final judgement in terms of "physical fitness for work" or, on the contrary, "unfitness", which, according to the regulations, is the sole datum relevant to the employer. So, physicians cannot reveal the number and type of clinical assessments, nor their results, the anamnesis and diagnosis (i.e. the worker's pathologies or affections). These are data about which the employer cannot be informed since they are considered as not useful and, therefore, beyond the scope of a subject's data interest.

With regard to the employer's *obligation* to protect the employee's health, sanitary controls are entrusted not to the employer but, rather, to a "competent physician" (Articles 25 and 38-42 of the Legislative Decree n. 81 of 9 April 2008, which has rearranged all regulations concerning health and safety protection at work in a "Unified Text", and so confirming the fundamental contents of the preceding regulations contained in Articles 16-17 of the Legislative Decree n. 626 of 19 September 1994)[1149]. The above mentioned controls include precautionary examinations (at the moment of duty assignment), periodical check-ups or when changing a duty. These examinations are aimed at expressing the "judgement of fitness for a specific duty" [Art. 41(2)]. This type of judgement, in spite of the assonance, indicates other than the above mentioned "physical fitness for work" of Art. 5 St.lav., since different is the judgement's aim which consists in assessing, from a sanitary point of view, the worker's fitness for "specific risks". Consequently, different is also the type of information to acquire which is intended, in case of precautionary examination, as a statement of «absence of any contra-indication to the duty that the worker is going to perform»; or, in case of periodical examination, as a check-up of the «physical and psychological integrity» of a worker assigned to a duty[1150]. So, it is up to the competent physician to choose the necessary examinations (which can consist of clinical and biological examinations, or diagnostic exams). Necessary, though, are to be considered only those examinations which are aimed at the evaluation of a possible specific professional "risk" involved by that particular duty [Art. 41(4)]. This determines the eventual relevance of different (and further) information with respect to that ordinarily requested for the evaluation of physical fitness for work, and eventually it determines

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[1149] L. Fantini, *Il medico competente e la sorveglianza sanitaria,* in M. Rusciano, G. Natullo (edited by), *Ambiente e sicurezza del lavoro,* Utet, Torino, 2007, p. 337.

[1150] This is, furthermore, specified by the same Legislative Decree n. 81/2008: according to which the sanitary controls consist in «all medical procedures aimed at the protection of workers' health and safety with regard to the workplace, professional risk factors and work performance procedures» [Art. 2(1m)]. This is the reason for which, for example, it establishes also the worker's obligation to undergo medical control at the end of a work relationship, in all cases reckoned by the laws in force [Art. 41(2e)]. On this subject see, M. Del Nevo, A. Del Nevo, *I limiti di legittimità dei certificati di idoneità alla mansione lavorativa,* in *Rivista Italiana di Medicina Legale*, 2004, p. 379.

also the legitimacy of special sanitary controls. Moreover, the physician has to transmit to the employer, in written form, only the final judgement about the worker's "fitness", "partial fitness" ("temporary" or "permanent", with "medical orders" or "limitations"), or "unfitness" ("temporary" or "permanent"), for the specific duty [Art. 41(6,8)]. On the other hand, the examinations' results have to be preserved in a sanitary and risk file which is set up, updated and kept by the physician, under his own responsibility. This obligation is valid for each worker who has undergone controls [Art. 25(2c) and Art. 41(5)], for whom the physician is also obliged to "professional secrecy" to keep against the employer [Art. 25 (1d)][1151] [and also against the responsible of risk prevention and protection and representative for the worker's safety: Art. 25(1i)]. In effect, the employer cannot be acknowledged of the worker's pathologies, eventually revealed by the examinations and which are the cause of the signaled fitness or unfitness. Neither can he be acknowledged of other possible health data contained in the file, since according to the regulations, the judgement represents all information that the employer needs in order to set up all precautionary and safety measures to protect his worker's health. Obviously, this precise aim, which has a precautionary and protective character concerning the worker's health, is the sole aim which can be attained by the employer who is therefore bound to respect only this purpose in the use of information[1152]. On the other hand, the worker – who is obliged to undergo the sanitary controls determined by the physician [Art. 20(1i)] – has the right to be informed by the physician about the meaning and the results of the examinations; the physician has the duty to issue, on request, a copy of the sanitary documents [Art. 25(1g,h)] and, in any case, the judgement of fitness or unfitness for duty [Art. 41(8)]. The worker is, therefore, the sole subject, besides the competent physician, who can access the content of his sanitary and risk file [Art. 25(1e)].

In both cases, not only when the worker's health control takes the form of a "power" given to the employer, but also when it expresses one of his "obligations", the regulations ascribe only to physicians the task to effectuate sanitary controls and to choose the necessary examinations. It denies this faculty to employers and, at the same time, it obliges the physicians to single out the examination purposes: purposes that can be functional only to the necessity of evaluating the fitness for work. Furthermore, the law establishes that the employer cannot be informed of the diagnosis (the worker's diseases), nor can he be informed of the examinations the worker has undergone. He can only receive a certification of fitness or unfitness for work or for specific duties. Other information – even the clinical motivations of the judgement – is put under the physician's professional secrecy. His intermediation between employer and employee, not only accounts for reliability, competence and objectivity of the examination, but also for the use of such modalities and cautions as to respect the person's dignity and privacy. The physician represents a filter who restricts the diffusion of information regarding the worker's health to the employer.

In the end, in these cases and in those defined by the law – generally to protect the worker's interest to benefit from the advantages – the communication to the employer concerning the

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[1151] Even for the peculiar case of workers exposed to carcinogenic, mutant, chemical or biological agents, the competent physician has to inform the employer only of the presence of an anomaly caused by this exposure, not the results of the sanitary examinations [Art. 242(4); Art. 229(6); Art. 279(3)].

[1152] This affects the possible consequences of an eventual judgement of the worker's unfitness for a specific duty. In this case the employer can only arrange the worker's removal from the exposure and, if possible, assign him to another duty considered as compatible to his health conditions [Articles 15(1m) and 42].

worker's or one of his relatives' pathologies (for example a disability) can be processed by the employer with the sole and specific aim for which information is revealed.

Regulations aim to limit as more as possible the employer's interference within the worker's privacy concerning health, so as to avoid any arbitrary, discriminatory or persecutory use of this type of information, which is eventually prejudicial to the worker's freedom and dignity. They restrict, as far as possible, the area of "juridical" relevance, in relation to work relationships, independently from what the employer really knows, by individuating, case by case, the relevant information. Such information is to be considered as sufficient to achieve the reckoned purposes, which are almost few in fact. Furthermore it defines, for each case, a legal data collection method (so as to consider as irrelevant all data collected in a different way, even if they are directly communicated to the employer), and the admitted purpose of processing, so as to implicitly forbid any other use of the worker's health data, in whatever modality obtained, and providing these provisions with criminal sanctions (see, Art. 38 St.lav.; Articles 55 and 58, Legislative Decree n. 81/2008).

By enforcing these general rules to genetic data – recently summarized by the same Garante in the «Guiding Principles Applying to the Processing of Employees' Personal Data for the Purpose of Managing Employment Relations in the Private Sector» of 23 November 2006 (Par. 3.3, 6.1, 6.2 and 6.5), and in the «Guiding Principles Applying to the Processing of Employees' Personal Data for the Purpose of Managing Employment Relations in the Public Sector» of 14 June 2007 (Par. 3.2 and 8.2), in accordance with the ILO Code of Practice of 1997 (Par. 10.8 and 10.9) and the COE Recommendation n. R(97)5 (Par. 3.2) – it is possible to affirm that the submission of a worker to genetic tests can be decided only by physicians, and therefore it cannot be ordered, nor simply suggested, by the employer. Neither can the employer receive any communication about the tests, nor can he be acknowledged of the type of tests the worker has been submitted to, or their results. It must also be added, that in any case, the submission to genetic controls is legal exclusively when they are considered as essential for the determination of the worker's fitness or unfitness for work. In any case, this proposition is generally difficult to maintain since, with regard to physical fitness for work according to Art. 5 St.lav, it is to be intended as "effective" and "actual" (not "eventual") fitness to perform a specific activity; whereas genetic tests, ordinarily, inform about a "future probability" to develop a disease, without defining a possible time of its onset. A slight relevance is given to genetic information when, on the contrary, it is aimed at the protection of the workers' health[1153].

b) As far as concerns the processing of the workers' data within the *labour market*, being this a phase which precedes pre-recruitment, the sole purpose of which is to put into contact employment demand and supply, the regulations actually confirm a normal irrelevance of information concerning matters of health and, so, of genetic data. In effect, Article 10 of the Legislative Decree n. 276 of 10 September 2003, prescribes the prohibition – sanctioned with criminal sanctions according to Art. 38 St.lav. [Art. 18(5)] – for all employment agencies (and all other authorized or accredited public and private institutions) to effectuate whatever inquiry or even data processing,

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[1153] S. RODOTÀ, *Tecnologie,* cit., p. 221; S. RODOTÀ, *Tra diritto e società. Informazioni genetiche e tecniche di tutela,* in *Rivista Critica di Diritto Privato*, 2000, p. 601-602; S. RODOTÀ, *La vita,* cit., 196.

or pre-selection, based among other on "health conditions", even with the worker's consent; unless they refer to characteristics affecting the performance modalities or, unless they represent a fundamental and determining requisite for the performance of the work activity [Art. 10(1)]; it further specifies that these prohibitions cannot, in any case, prevent the subjects mentioned to provide specific services or target actions in order to assist disadvantaged workers who are looking for an employment [Art. 10(2)].

It is evident, from a thorough reading of the rule, that the exceptions to the general prohibition of data processing concerning workers' health, demand either a not easy to prove evidence of its indispensability during the "recruitment" of workers, or are aimed at the acknowledgement of the worker's right to benefit from an advantage or a preference in obtaining an employment, such as in the case of disabled person. In both cases, reference is made to the "actual" and "ascertainable" workers' health conditions and not, for sure, to a "possible" condition registered by the genetic makeup.

c) Finally, as far as concerns the *social security* sector, the *public system* inclines towards the exclusion of any possibility to use workers' genetic data.

In general, from the regulation concerning the benefits for *old age and survivors pension* (and also involuntarily unemployed allowances), it is possible to deduce a substantial irrelevance of the workers' health data with reference to the amount of contributions or benefits. Ordinarily, the contribution scheme is proportioned to the remuneration, and benefits are proportioned to the contribution scheme (Art. 1, Law n. 335 of 8 August 1995).

Even in case of social benefits whose allowance depends on the physical and/or psychological condition of the worker – i.e. protection against *accidents at work and occupational diseases*, and also *disablement*, deriving or not from occupational reasons and, moreover, *illness* – the workers' health conditions are uninfluential for the settlement of the contribution, which even in this case is proportioned to remuneration. Furthermore, only in case of insurance premium related to occupational accidents and diseases, the contribution is proportioned to the national medium risk of each insured work, to the company's accident trend and to the respect of the regulation concerning health and safety at work (Articles 28, 40 and 41, Presidential Decree n. 1124 of 30 June 1965; Art. 3, Legislative Decree n. 38 of 23 February 2000). Health conditions are, on the contrary, relevant for the allowance of a benefit, with exclusive reference to already developed diseases, or already contracted illness, to infirmity and physical or mental evident impairment. In this case evaluation must be done of: total or partial degree of impairment; reduction percentage affecting the subject's capacity-aptitude for work (or impairment of physical and/or mental integrity); temporariness or permanence; presence of eventual concomitant causes (already present or occurred). On the contrary, the subject's predisposition to contract a disease has no implication on the allowance or the amount of the benefit (Articles 2, 3, 52, 68 and 74, Presidential Decree n. 1124/1965, and Articles 10 and 13, Legislative Decree n. 38/2000; Articles 1 and 2, Law n. 222 of 12 June 1984). This is valid even in case of occupational diseases, where relevance is given to the connection between the execution of a duty and the cause of the disease or its correlation with the type of work, hence the evidence of the occupational cause – by now also merely probable or possible – [Art. 3(3) Presidential Decree n. 1124/1965; Art. 10(4) Legislative Decree n. 38/2000], which can be excluded solely in case of acknowledgement of a genetic monofactorial disease.

The threat of an undue use of genetic data is more concrete in the sector of *integrative social security*, since the funds are mainly run by private agencies. In this sector there is more freedom to determinate the terms of access to this system, since the law in force (i.e. the recently issued Legislative Decree n. 252 of 5 December 2005) puts no limits or prohibitions in relation to the fixation of the benefit and of the contribution quantum [the matter has been referred to the collective agreements, with the specification that the quantum has to be indicated in fixed terms or in percentage: Art. 8(2)]. Indeed, in this case, relevance is given to the holder's health, in particular to his or her longevity, in order to determine the grants' length, the calculation of income and, even, the predictability of the possibility to «enter into collateral insurance contracts against risk of death or survival to average life expectancy» [Art. 11(5)]. Moreover, the legislation allows to build up pension funds that «cover bio-metrical risk» [Art. 7 bis(1), implemented by Art. 4 of the Legislative Decree n. 28 of 6 February 2007]; it establishes further that the individual pension schemes can be even set up with «life insurance agreements», without regulating the terms of contribution and benefit (Art. 13).

7. Confirmation and integration of workers' protection made by the general regulation on the protection of personal data (Legislative Decree n. 196/2003). Irrelevance of the workers' consent and unlawfulness of Art. 46(3), contained in the Medical Code of Practice of 16 December 2006.

The rules deduced from the labour law are, as a matter of fact, consistent with the general principles regarding the protection of personal data, as set out by the Legislative Decree n. 196/2003, which assimilates the principles contained in the Directive 95/46/CE of 24 October 1995 on the Protection of Individuals with regard to the Processing of Personal Data and on the Free Movement of such Data. In particular, it refers to the: principles of necessity, lawfulness, and fairness of data processing; principle of purpose; principles of accuracy and update, of proportionality (i.e. relevance, completeness and non-excessivity of data in relation to the purposes for which they are collected or subsequently processed), and of data keeping in a form which permits identification of the data subject for no longer than is necessary for the purposes for which the data were collected or subsequently processed [Articles 3 and 11(1)]. Furthermore, with specific reference to sensitive data, there is the principle of indispensability of processing with regard to the purposes sought in the individual cases [Art. 22(3,5,9)]; and, finally, the general prohibition to use personal data processed in breach of the relevant provisions concerning the processing of personal data [Art. 11(2); confirmed by Art. 22(5), concerning sensitive data].

The general ruling on the protection of personal data adds, moreover, further instruments to protect genetic data processing as allowed by special regulation: the right of the data subject, to access data, to rectify and integrate data, to erase, to transform anonymously, or to block such data that have been processed unlawfully, and to object, on legitimate grounds, to the processing of personal data (Articles from 7 to 10)[1154]; the obligation to information to data subject (Art. 13); the obligation to destroy data after their processing, unless data is kept or assigned to another data controller, provided they are intended for processing under terms that are compatible with the purposes for which the data have been collected, or for historical, scientific or statistical purposes (Art. 16); also, the security requirements on data processing [Articles 31 and from 33 to

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[1154] Among the data subject's rights the case of "update" seems to be inapplicable, since genetic data do not change or grow old, i.e. there is no risk of obsolescence and so there is no need to update.

36; and Annex B), containing the «Technical Specifications concerning Minimum Security Measures»], with special reference to all measures specifically set up for sensitive data and, among these, personal data disclosing health [Art. 22(6,7); Par. 5, 17, 19, from 20 to 24, 28 and 29, Annex B]; the obligation of precautionary notification to the Garante [Art. 37(1a) and Art. 38; Garante's Decision n. 1 of 31 March 2004]; rules regarding the transfer of data abroad (Articles from 42 to 45); all rules specifically set up for sensitive data, such as the authorization expressly stated by law and the pursuit of aims having a relevant public interest, when processing is made by public subjects (Art. 20; as far as concerns employment and social security, these aims are defined by Art. 112) and, on the other hand, the subject's written consent and the Garante's Authorization, in case of data processing by private subjects [Art. 23(4) and Art. 26]; moreover, the even more specific rules concerning the processing of data disclosing health conditions, in the health care sector, i.e. health care professionals and public health care bodies [Articles from 75 to 94]; the obligation to collect sensitive data, as a rule, from the data subject [Art. 22(4)]; the prohibition to disseminate data disclosing health [Articles 22(8) and 26(5)]; the so-called "equal rank clause", according to which the processing of health data, which is necessary for carrying out the investigations by defence counsel, or else to establish or defend a legal claim, is legal only when said claim is not overridden by the data subject's claim, or else consists in a personal right or another fundamental, inviolable right or freedom [Art. 26(4c)]; administrative and alternative protection in respect to judicial protection, granted by the Garante (Articles from 141 to 151), and the special judicial protection (Art. 152); finally, the sanctions, including the civil claim for damages according to Art. 2050 c.c. (Art. 15), and also administrative (Articles from 161 to 166) and criminal sanctions (Articles from 167 to 172).

When we refer these numerous rules to the employment sector, the following indications could be of help: the two already mentioned general rules issued by the Garante, containing the "Guiding Principles" for the processing of employees' personal data in the private (in particular, with reference to workers' health data: Par. 3.3, 6 and 8.1) and public sectors (in particular: Par. 3.2, 6 and 8). The above mentioned rules, not only summarize the entire labour law scheme, but also lay down further practical rules of conduct, deduced by interpretation from the Legislative Decree n. 196/2003. Most important of all, we are waiting for the approval of a «Code of conduct and professional practice by public and private entities for the processing of personal data for social security purposes or in connection with management of employer-employee relationships», in acknowledgement of the standards contained in the Council of Europe Recommendations [Articles 12(1) and 111, Legislative Decree n. 196/2003]: i.e. Recommendation n. R(86)1 of 23 January 1986, on the Protection of Personal Data used for Social Security Purposes; and Recommendation n. R(89)2 of 18 January 1989, on the Protection of Personal Data used for Employment Purposes (above all, Par. from 10.1 o 10.6, on the processing of workers' health data).

As far as concerns the enforcement of the general law regarding the protection of personal data on labour law, it is necessary to be more precise. In particular, because of the principle of *lex specialis*, the worker's written consent – in accordance with the general rules on genetic data processing in the private sector – is not effective in order to overcome all prohibitions and limits issued by special labour laws[1155]. In these terms, the irrelevance of the worker's consent derives from the inviolability of his privacy, that the legislator has preserved from the parties' availability,

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[1155] P. CHIECO, *Privacy e lavoro. La disciplina del trattamento dei dati personali del lavoratore,* Cacucci, Bari, 2000, pp. 38 ss. e 158 ss.

even from the interested party, in order to protect his interests. By means of compulsory laws, following an heteronomous way, the legislator has delimited the flow of information possibly going on between employer and employee: this action is founded on the system's presumption that, in general, that of the worker is not a free manifestation of his own will[1156]. Such a remarkable restriction of private autonomy is, therefore, justified by the exigency to protect the weakest party. The aim is to correct the lack of balance between the parties, by limiting the employer's power so that it cannot be of prejudice to any person and to the worker's dignity and freedom, since it remains dubious whether the worker's, and moreover, the applicant's consent is really spontaneous.

Therefore, only for the cases of processing allowed by the legislator, can the health care professionals ask for the worker's consent, so forming the so-called "right to informed self-determination": since it is not possible to impose genetic tests by coercive means, with respect to Art. 32(2) Cost.

This is consistent not only with the general statement about the freedom and specificity requisites of consent [Art. 23(3), Legislative Decree n. 196/2003; Point 6 of the Garante's Authorization for the Processing of Genetic Data of 2007; Art. 6, Par. 1, UNESCO Universal Declaration on Bioethics and Human Rights, adopted on 19 October 2005], but also with the main issue of the Legislative Decree n. 196/2003, from which it is to be deduced that the validity of the data subject's consent is subordinate to the respect of the principle of "lawfulness" of processing [Art. 11(1a) and Art. 23]. Moreover it is consistent with the textual enunciation on the prevalence of any laws or regulations laying down more restrictive limitations or prohibitions on the processing of certain personal data [Art. 184(3)], such as those issued by labour law containing a higher protection of the workers' data.

According to the above remarks, it is therefore necessary to point out the unlawfulness, because it is in contrast with the principles and rules above mentioned, of Art. 46(3) of the Italian Medical Code of Practice of 16 December 2006 (integrated on 23 February 2007). According to this Article, «physicians shall not perform any genetic or predictive test for insurance or employment purposes, without an expressed and aware manifestation of will made by the interested citizen who is the sole recipient of information». This rule, which ascribes to the worker's consent a legitimization function that the same consent cannot contain, deserves a careful re-examination, also in consideration of the special delicacy of the role that labour law has given to physicians[1157].

8. The necessity of a proper law discipline on genetic data processing for employment purposes.

Having thus established the enforceability of labour law discipline concerning workers' health, on genetic data processing (integrated, as far as possible, by the Legislative Decree n. 196/2003) –

[1156] See the EU Article 29 Data Protection Working Party Opinion n. 8/2001 of 13 September 2001, on the Processing of Personal Data in the Employment Context (Par. 8 and 10). See also, A. BELLAVISTA, *Le prospettive della tutela dei dati personali nel rapporto di lavoro,* in *Scritti in onore di Giuseppe Suppiej,* Cedam, Padova, 2005, p. 43; S. RODOTÀ, *Tecnologie,* cit., 222; S. RODOTÀ, *Tra diritto,* cit., p. 602; S. RODOTÀ, *La vita,* cit., p. 196. About this subject, see M.N. BETTINI, *Il consenso del lavoratore,* Giappichelli, Torino, 2001, p. 45 ss.

[1157] C. CASONATO, *La discriminazione*, cit., p. 666. See also, M. BARNI, *Un codice deontologico di chiara sostanza medico-legale,* in *Rivista Italiana di Medicina Legale*, 2007, p. 543; V. DURANTE, *Salute e diritti tra fonti giuridiche e fonti deontologiche,* in *Politica del Diritto*, 2004, p. 563; G. IADECOLA, *Le norme della deontologia medica: rilevanza giuridica ed autonomia di disciplina,* in *Rivista Italiana di Medicina Legale*, 2007, p. 551.

which has to be considered as prevailing on the Garante's Authorization on genetic data processing – there can be no doubt that a specific discipline on workers' genetic data processing, founded on the international orientation in this matter, would give more enforceability to all principles and rules regarding workers' health. The reason is to be found in the particularity of this type of information which needs a special regulation.

In this way, and first of all, the same concept of workers' "health" is going to change, as well as the meaning of "physical and psychological fitness", which does not constitute anymore a mere contingent factor, dependent on the actual conditions of the worker. On the contrary, the concept of fitness is going to be concerned also by the worker's future health conditions, which are evaluated in a future perspective, dependent on an assessment which takes into account not only the already developed pathologies but also pathologies which could probably develop in future.

An appropriate regulative proposal could be similar to that adopted by the legislator in case of AIDS (Articles 5 and 6, Law n. 135 of 5 June 1990, integrated by the additive judgement of the Italian Constitutional Court n. 218 of 2 June 1994[1158]), drug addiction (Articles 124 and 125, Presidential Decree n. 309 of 9 October 1990)[1159] and alcoholism (Art. 15, Law n. 125 of 30 March 2001); furthermore, it could be inspired by the broad protection granted against discrimination on the grounds of disability (Legislative Decree n. 216 of 9 July 2003, implementing the Directive 2000/78/CE of 27 November 2000) and racial or ethnic origin (Legislative Decree n. 215 of 9 July 2003, implementing the Directive 2000/43/CE of 29 June 2000).

With an effort of imagination, the legislator should proceed towards a standardization of the cases concerning the very peculiar duties performed by the worker or concerning his working context, in which the use of genetic data should be considered as essential, and therefore allow the use of genetic tests either to control the worker's physical and psychological fitness, or aimed at the protection of health at work. Such cases could be, for example, the performance of activities implying third parties' safety and health risk, or those implying an elevated risk of accidents at work or occupational diseases with genetic origin (even if only partial), i.e. which could injure one's own or third parties' integrity, or when the pathology is absolutely against the worker's assignment to a certain workplace; other cases, that need to be stated, are all those duties – because of their nature or because of the context in which they are performed – for which genetic features constitute an essential and determining requirement for the their execution, since they demand determined physical or psychological qualities and aptitudes[1160]. In the same way, it is necessary to define a strict list of cases for which it should be allowed to use the genetic data of the worker or of his relatives, in order to grant the worker with benefits, to promote special needs or to prevent or compensate eventual disadvantages.

[1158] M. Aimo, *Aids e lavoro alla luce della recente giurisprudenza italiana e comunitaria,* in *Lavoro e Diritto*, 1996, p. 347 ss.; B. Caruso, *Le nuove frontiere del diritto del lavoro: Aids e rapporto di lavoro,* in *Rivista Italiana di Diritto del Lavoro*, 1998, I, p. 105; S. Nespor, *Divieto di discriminazione, eccezione al divieto e obbligo di discriminazione: la Consulta sulla legge n. 135/1990,* in *Corriere Giuridico*, 1994, p. 1095; A. Topo, *Minorità psico-fisiche e lavoro:* handicap, *sieropositività, tossicodipendenza,* in F.A. Cappelletti, L. Gaeta (edited by), *Diritto lavoro alterità. Figure della diversità e modelli culturali,* Esi, Napoli, 1998, p. 251.

[1159] A. Ascione, *Tossicodipendenza, sieropositività ed Aids conclamata: garanzie e tutela nel rapporto di lavoro,* in *Diritto e Giurisprudenza*, 1996, p. 308 ss.; A. Topo, *La tutela del lavoratore tossicodipendente,* in *Rivista Italiana di Diritto del Lavoro*, 1993, I, p. 247.

[1160] C. Casonato, *La discriminazione*, cit., p. 664.

Except for these particular cases, it should be confirmed a general prohibition, with criminal sanctions, to make any inquiry or processing of the workers' or applicants' genetic data – destined not only to employers but also to all public and private subjects who process workers' information for employment or social security purposes, including health care professionals – or to make any discrimination based on such data, including the genetic features into the factor catalogue of Art. 15(2) St.lav., with the subsequent nullity of the acts or agreements made by the employer.

The entire subject should be withdrawn from the individual autonomy and from the worker's disposal, in order to resist to all commonplaces concerning the workers' consent to data processing since, for workers, it does not constitute a guarantee. From this point of view, the matter has been entirely restructured by the general regulations contained in the Legislative Decree n. 196/2003, by granting heteronomous guarantees (Articles 24 and 26).

Therefore, also in case of allowed genetic assessments, the law should propose special devices aimed at the protection of the workers' freedom, dignity and privacy. These devices are necessary because of the discriminatory potentialities and stigmatization threats concerning not only the worker's professional life (made by the employer and also by his workmates) but also, in general, affecting his or her social life. In effect, it should be precisely stated that: the use of genetic tests cannot be made after the worker's initiative, nor should it be proposed by the employer; it should be exclusively determined by physicians, always motivated by reasons of absolute inevitability of these type of exams and, therefore, limited to such exams as to provide with information strictly inherent with the specific response that is going to be issued (i.e. concerning single pathologies, better if their certain onset can be predicted or that possess a high probability degree of onset), so as to avoid wide-area surveys; moreover, such controls should be made only by physicians who are bound to their professional secrecy, with the obligation to communicate the results exclusively to the person that has undergone such examinations and with the prohibition to reveal to the employer not only the test results but also the same fact that they have been made; in any case, the employer can receive only the final certification of fitness or unfitness for work, without revealing genetic pathologies or anomalies.

Furthermore, the use of genetic examinations according to law represents an obligation for the worker, just like all cases of direct prescription by the law or, in any case, after the physician's decision. Therefore it becomes necessary to regulate the effects of an eventual refusal, expressed by the worker, to undergo any test and his subsequent opposition to data processing. Obligatoriness means not to constrain a subject against his own will; but it is also true that the worker's refusal hinders an evaluation of his or her fitness for work. This could legitimate the employer's non-recruitment during the recruitment phase and, indeed, the application of sanctions against the worker or even his or her dismissal.

In the same way, a regulation is needed concerning the consequences of an eventual judgement of total or partial unfitness for work evaluation, based on the results of genetic surveys.

In both cases, given the problem's analogy, the legislator should indicate all eventual remedies to the employees' difficulties, and the connected legal actions. In this matter, it would be reasonable to establish an obligation, for the employee and in his or her own interest, to take caution (and, eventually to submit to health care), according to medical prescription, if this actions allow to get around any risk and compensate his or her unfitness for work. If it is not possible to take this action, or if the employee does not agree with it, the employer should be entitled, at first, to adopt a termination-of-service arrangement regarding the performance of a specific duty, accompanied by the charge to find him or her another job assignment; dismissal should be justified only if the employer demonstrates the impossibility to assign the worker to another duty[1161].

Without any doubt, the legislator should be concerned by the problem, peculiar to labour regulations, concerning the limitation of the power exerted on workers. It would be useful to define what information can be collected and processed, and which are the lawful aims of processing, by confirming the prohibition to use data in all cases and for all purposes other than that allowed by the law.

Furthermore, the legislator should take into account another concern, i.e. that relating to the "modalities" of data processing. It would be useful to establish guarantee procedures[1162]: the obligation for physicians to give to workers detailed preventive information about types and possible results of tests, together with an appropriate genetic counseling. It is also necessary, for the physicians, to fix the communication limits as far as concerns the workers' genetic data, by excluding its automaticity, by referring to the worker the choice of knowledge and by requesting a clear and free expression of will on the part of the worker (the so-called "right not to know")[1163].

Moreover, there still remains the problem concerning rule's effectiveness, i.e. mechanisms and instruments which can guarantee their respect, in particular during the pre-recruitment phase and with the aim of avoiding any discrimination inherent to genetic data. Besides the traditional "defensive" technique consisting of a series of prohibitions and relative sanctions, together with a special jurisdictional protection against discrimination (such as contained in Articles 4 and 5 of Legislative Decrees n. 215/2003 and n. 216/2003), it should be adopted a "promotion technique" by means of a series of "positive" sanctions and incentive measures. Examples are: social clauses containing economic benefits or the possibility to participate in public contracts addressed to the employer who acts in respect of the regulations; positive actions and reductions aimed at the recruitment of workers who carry ascertained genetic anomalies (eventually by their inclusion into the category of the so-called "disadvantaged workers", according to a Communitarian notion which is also being absorbed by the national legal system[1164]), which can be borrowed from the rules concerning the right to work of disabled persons.

With regard to this matter, the trade unions could play an important supervision role in order to control that all rules are being respected. On the other hand, the collective bargaining could perform a task of rule specification, in order to better protect the worker[1165]. In the same way, all forms of social control could be useful, such as that exerted by consumers and, in particular, by consumers' associations, in order to broaden the corporate social responsibility culture.

Finally, there remains the necessity to regulate the sector of integrative social security by stating the irrelevance of genetic data, since the examinations inhering the genetic status of a worker

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[1161] A. COLONNA, *Il controllo medico dell'inidoneità sopravvenuta del lavoratore,* in *Il Diritto del Lavoro*, 2001, I, p. 24.

[1162] G. SANTANIELLO, C. FILIPPI, *Dati genetici,* cit., pp. 542-543.

[1163] L. FIORENTINO, *La medicina predittiva e il diritto all'ignoranza nei test genetici presintomatici,* in *L'Arco di Giano*, 2002, n. 31, p. 173; S. RODOTÀ, *Tecnologie,* cit., p. 121; J. WILSON, *To Know or Not to Know? Genetic Ignorance, Autonomy and Paternalism,* in *Bioethics*, 2005, p. 492 ss.

[1164] M.V. BALLESTRERO, G.G. BALANDI (edited by), *I lavoratori svantaggiati tra eguaglianza e diritto diseguale,* il Mulino, Bologna, 2005.

[1165] U. ROMAGNOLI, *Privacy e rapporti di lavoro,* in G. RASI (edited by), *Da costo a risorsa. La tutela dei dati personali nelle attività produttive,* Istituto Poligrafico e Zecca dello Stato, Roma, 2004, p. 160.

and their consequences on the amount of contributions and benefits, could discourage the workers to agree with this type of funds. This would be contrary to the actual trend of the Italian social security system, as expressed by the prospective changes in legislation (in particular, with reference to the Law n. 243 of 23 August 2004) which, rather, promote the recourse to integrative social security as an instrument of resolution of the financial crisis of the public social security system.