



Some social and ethical aspects of DNA analyses and DNA profile databases

Joaquín-Jose Gamero ^{a,*}, Jose-Luis Romero ^a, Juan-Luis Peralta ^a,
Monica Carvalho ^b, Maria-Conceição Vide ^b, Francisco Corte-Real ^c

^a *Departamento Medicina Legal, Facultad de Medicina, University of Cádiz, Plz. Fragela s/n Cádiz, 11003, Spain*

^b *Institute of Legal Medicine of Coimbra, 3000 Coimbra, Portugal*

^c *National Institute of Legal Medicine, Largo da Sé Nova, 3000-213 COI, Coimbra, Portugal*

Abstract. There is general agreement concerning the fact that research into human genetics can affect the community as a whole, and for this reason it is necessary for society, and not only scientists, to discuss and decide on what they wish to accept and what they wish to reject. In this paper, the degree of information a representative sample of the Spanish population has with regard to DNA profiles is analyzed, as well as the point of view this population holds concerning the criteria of reliability, quality, precision and security that must be established for the analysis and protection of stored forensic genetic data. Finally, the population's opinion concerning other questions relevant to this subject is also sought. © 2005 Elsevier B.V. All rights reserved.

Keywords: National DNA database; DNA profile; Public opinion; Forensic genetics; Ethics

1. Introduction

There is general agreement about the fact that research investigation into human genetics can affect the community as a whole [1], and for this reason it is necessary for society, and not only scientists to discuss and decide on what they wish to accept and what they wish to reject [2]. It thus seems clear that there is a need in Spain to examine and define the social and individual interests faced. In short, the aim of this study, in accordance with the International Declaration on Human Genetic Data [3], as well as with the plan of action “Science and Society” of the European Commission [4] is to reveal the degree of information and criteria society has with regard to a question that may affect it in specific circumstances.

* Corresponding author. Tel.: +34 956 015 187; fax: +34 956 223 139.

E-mail address: joaquin.gamero@uca.es (J.-J. Gamero).

Indeed, it is of great interest to take into account the opinions of different social groups before adopting legal decisions related with biotechnology given that, in order to reach consensus, information should flow in two directions, Society–Science [5].

In this paper, the degree of information a representative sample of the Spanish population has with regard to DNA profiles is analyzed, as well as the point of view this population holds concerning the criteria of reliability, quality, precision and security that must be established for the analysis and protection of stored forensic genetic data. Finally, the population's opinion concerning other questions relevant to this subject is also sought.

2. Materials and methods

The following sequence has been used to carry out this work: (a) the drawing up of a questionnaire with a uniform standard of comprehension; (b) the selection of a uniform group of interviewers with a high standard of education; (c) the selection of a random sample employing stratified sampling in order to achieve appropriate representation for sex, age groups, educational standards and types of professions; (d) the treatment of non-random errors that are unconnected with sampling; (e) the statistical analysis of the data, which implies: tabulation, graphical representation and synthesis with the aid of the computer software Statgraphics Plus 5.1 (Statistical Graphics Corp. 1994–2001). The chi-square test was done to analyze the responses by sex, age and professional group [6–8].

3. Results

As for the reliability of the techniques and analyses used, which may stem from the analyses of the polymorphisms of decoded DNA, mention must be made of the interviewees' opinion about such techniques. A high percentage of interviewees (86.90%) expressed an opinion about the efficiency of the techniques for the identification of individuals by means of so-named genetic fingerprinting.

Public opinion was obtained on the need to create clear and specific regulations that specify the differing types of offences which justify the storing of genetic material in DNA profile databases without the consent of the offenders. The DNA profiles would then be employed in penal or criminal processes. It must be pointed out that 87.64% of the surveyed population agreed with the latter question although significant differences were observed ($p=0.0008$) when it was put to the different professional groups.

Public opinion was surveyed with regard to the need for regulations which, as in the case of DNA profiles, would clearly specify in which cases genetic samples and tissue from individuals involved in penal cases should be stored. Such material may then be analyzed by means of the state of the art techniques available. 87.43% of those surveyed considered such regulations necessary. Likewise, the significant differences observed ($p=0.0008$) when the question was put to the different professional groups must be pointed out.

The survey carried out attempted to sound out opinion regarding the need to regularly update the protocols that regulate all those questions of a technical nature concerning extraction, analysis and storage in line with the development of forensic genetics. Among such questions, the types and numbers of markers used for cases of genetic identification may be mentioned as an example. In this sense, 81.06% of the surveyed population backed such a measure. When all the professional groups involved in this study are taken into account, the discrepancies among them may be explained by the percentage of “don't know/no replies” given by those professions related to law and local/state security agencies (compared to those percentages obtained for other professions).

93.28% of the interviewees were in favour of legislation that regulates minimum quality and security requirements for the laboratories that deal with this type of analysis.

Another of the questions put to the surveyed population referred to the possible need to maintain the anonymity of biological samples for the professionals who work in laboratories with such samples. In other words, restrict the level of access to only the data that is strictly necessary for them to carry out their professional work. 75.74% of the interviewees agreed that the samples should remain anonymous.

4. Conclusion

Taking into account the different opinions existing among the different professional groups in the study carried out, it appears to be necessary that those who are to form part of the National Commission for the forensic use of DNA (Organic law 15/2003, BOE no. 283, 26th of November 2003) should be composed of members of different academic disciplines and from different institutions or are involved in the use, application or analysis of DNA (social representatives, representatives of those individuals who may be affected by the measures that are adopted, scientific societies, state security corps, laboratories working for state security corps, laboratories working for the ministry of justice, laboratories authorized to carry out this type of specialist report, ethics experts).

Finally, one can appreciate the importance of collecting opinions on decisions regarding general policies for the collection, treatment, use and preservation of human genetic data as well as the evaluation of data management, not only from the society all these processes will be aimed at [3,4] but also from the laboratories implied in the processes in the analysis of genetic data of criminal origin. In this way, any distrust or suspicion among the public with regard to regulations affecting DNA analysis in criminal investigation may be dissipated, while the degree of relevant information and the criteria made available is increased. By means of the collection of said opinions it would be possible to establish a minimal framework that would serve as a base for the establishment of the so called “type codes” [9] or “conduct codes” (Directive 2002/58/CE of the European Parliament and Council, of the 12th of July 2002, concerning privacy and electronic communications) which, once registered in the General Registry of Data Protection (article 32.3) [9] may be subject to complementary measures. This would improve the application and interpretation of the law [9] while extending guarantees and establishing, albeit within the limits of the field of forensic genetics, compliance with and respect for the principles and rights recognized by law [9].

References

- [1] C.M. Romeo-Casabona, Introduction, *Journal of Law and Human Genetics* 1 (1994) 16–20.
- [2] M. Guillen, et al., Ethical-legal problems of DNA databases in criminal investigation, *Journal of Medical Ethics* 26 (2000) 266–271.
- [3] Declaración Internacional sobre datos Genéticos Humanos, Comité Internacional de Bioética, UNESCO, París, 2003.
- [4] Comisión Europea Plan de acción “Ciencia y Sociedad”, Comunidad Europea, Bélgica, 2002.
- [5] V. Camps, E. Giralt, *The Social Perception of Biotechnology*, Fundació Víctor Grífols i Lucas, Barcelona, 2001.
- [6] F. Azorin, J.L. Sanchez-Crespo, *Métodos y aplicaciones del Muestreo*, A.U.T., Madrid, 1986.
- [7] W.G. Cochran, *Técnicas de muestreo*, CECSA, México, 1971.
- [8] L. Kish, *Muestreo de encuestas*, Ed. Trillas, Madrid, 1972.
- [9] Ley Orgánica 15/1999, de 13 de diciembre, de Protección de Datos de Carácter Personal, (BOE núm. 298, de 14–12–1999, pp. 43088–43099).