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"Would you accept having your DNA profile inserted in the National Forensic DNA database? Why?" Results of a questionnaire applied in Portugal

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ABSTRACT

The creation and expansion of forensic DNA databases might involve potential threats to the protection of a range of human rights. At the same time, such databases have social benefits. Based on data collected through an online questionnaire applied to 628 individuals in Portugal, this paper aims to analyze the citizens' willingness to donate voluntarily a sample for profiling and inclusion in the National Forensic DNA Database and the views underpinning such a decision.

Nearly one-quarter of the respondents would indicate 'no', and this negative response increased significantly with age and education. The overriding willingness to accept the inclusion of the individual genetic profile indicates an acknowledgement of the investigative potential of forensic DNA technologies and a relegation of civil liberties and human rights to the background, owing to the perceived benefits of protecting both society and the individual from crime. This rationale is mostly expressed by the idea that all citizens should contribute to the expansion of the National Forensic DNA Database for reasons that range from the more abstract assumption that donating a sample for profiling would be helpful in fighting crime to the more concrete suggestion that everyone (criminals and non-criminals) should be in the database. The concerns with the risks of accepting the donation of a sample for genetic profiling and inclusion in the National Forensic DNA Database are mostly related to lack of control and insufficient or unclear regulations concerning safeguarding individuals' data and supervising the access and uses of genetic data.

By providing an empirically-grounded understanding of the attitudes regarding willingness to donate voluntary a sample for profiling and inclusion in a National Forensic DNA Database, this study also considers the citizens' perceived benefits and risks of operating forensic DNA databases. These collective views might be useful for the formation of international common ethical standards for the development and governance of DNA databases in a framework in which the citizens' perspectives are taken into consideration.

1. Introduction

The databases containing a large number of genetic profiles used to fight crime have expanded considerably in a rapid and far-reaching way in Europe and beyond. Today, according to the NGO Forensic Genetics Policy Initiative, 60 countries operate National Forensic DNA Databases and others are being expanded or newly established in at least 34 additional countries, although reliable data are missing for some countries [1]. The European Network of Forensic Science Institutes (ENFSI) reported data related to National Forensic DNA Databases operating in 26 countries in Europe [2].

Forensic DNA databases can help fight crime more efficiently, have proved to be a valuable tool in assisting in the enforcement of law and preventing miscarriages of justice [3], and are potentially useful for deterring offenders from further criminal activity [4]. Therefore, advisory groups have been formed in Europe and elsewhere to improve the harmonisation of forensic DNA methods

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in order to facilitate the sharing of data across national boundaries [5–8].

At present, a considerable investment is being made to reinforce international cooperation and exchange genetic information to combat crime and terrorism through the so-called Prüm Treaty [9] which was established August 2011 as the deadline for all Member States to render their forensic DNA databases searchable for other member states (on a match/no match basis). The increasing mobility of people in the EU renders technical, legal and political harmonization necessary in terms of the handling of DNA databases, but efforts to create common ethical standards for the content and use of DNA databases should also be made in order to ensure that human rights are respected [10–12].

Although the value of forensic DNA databases is recognized widely by criminal justice policymakers and legislators, there are academic, legal, and civil society groups that have reacted critically to the expansion of databanks holding genetic material for criminal investigation purposes. Critics argue that operating forensic DNA databases involves potential threats to the protection of a range of human rights, in particular liberty, autonomy, privacy, informed consent, moral and physical integrity and the presumption of innocence [13–18], and that the expansion of these databases might be perceived by the population in general as excessive state control [13,19]. Thus, a responsible forensic DNA database policy needs to find a reasonable balance between these two positions, based on the creation of a moral and ethical spectrum involving both professionals in the area of forensics and law enforcement [20] and the public [13], in particular, social groups which are less involved in genetics [21].

In order to provide an empirically-grounded assessment of individual perceptions and collective attitudes to the risks and benefits of operating forensic DNA databases, an online questionnaire was carried out in Portugal. Our specific aim is to analyze the citizens' willingness to donate voluntarily a genetic sample for profiling and inclusion in the National Forensic DNA Database and the views informing such a decision. The Portuguese DNA database was formally created under legislation passed in 2008 and combines the purposes of civil identification and criminal investigation [22]. The custodian of the DNA database is the Ministry of Justice, while the National Institute of Legal Medicine (NILM) is the institution responsible for processing the data (samples and profiles) and for communicating the results of analyses to the competent judicial authorities. It contains several subcategories of DNA profiles, including volunteers, professionals who collect and analyze samples, unidentified corpses, missing persons or their relatives, crime scene stains, formal suspects and persons convicted and sentenced to three years or more in prison. DNA samples from formal suspects and persons convicted and sentenced to no fewer than three years in prison can only be collected pursuant to a judicial order. Samples from unidentified corpses, missing persons and crime scene stains can be collected by the law authorities. According to Portuguese Law the volunteer is someone who wishes to donate a sample (article 6.1 of Law 5/2008). The DNA profiles collected from volunteers are to be preserved for an unlimited time and removed only in the case of explicit revocation of the previously given consent. The collection of samples from volunteers is to be made with free, informed and revocable consent (article 18.1a-b of law 5/2008) and following a sample collection request in writing, which must be addressed by the volunteer to the National Institute of Forensic Medicine (no. 2 of article 6 of Law 5/2008).

2. Materials and methods

This study is based on a questionnaire developed by the research team. It was uploaded onto the project's website between October and December 2012. Participation was requested through the mailing lists of five public universities and research centres situated at different geographical points in Portugal. The authors also asked relatives, friends and colleagues to distribute the questionnaire among their own networks. A total of 711 questionnaires were completed, with participants aged from 17 years. The questionnaire comprised six main sets of questions covering the following areas: 1. Information about the National Forensic DNA Database: sources of knowledge, assessment of information about the DNA database provided by the government and the media, and opinion about how the media should be involved in disseminating information to the public; 2. Perception of the benefits and risks of the forensic DNA database; 3. Assessment of the efficiency of DNA technology and the value of DNA evidence in court; 4. Opinion about regulation of the forensic DNA database: custody, access, criteria for insertion and deletion of profiles; 5. Willingness to accept the insertion of the individual's own profile in the National Forensic DNA Database (categorized as yes, perhaps, no) and the reasons underlying such an answer (open-ended question); 6. Socio-demographic characteristics (e.g. gender, age, education and profession). For the purposes of this paper we shall discuss only the results obtained from questions included in the last two areas.

In order to analyze the variations in the results obtained through the questions "Would you accept having your DNA profile inserted in the National Forensic DNA Database? Why?", we considered the variables of gender, age, educational level and professional group. The latter variable was excluded from our analysis because almost one third of the participants (31.8%) did not report that information. Furthermore, there were no significant differences in terms of voluntarily accepting DNA profile insertion when the results were analyzed according to the professional group ($p = 0.716$). Among those who declared their profession ($n = 485$), 14.0% worked in the field of law enforcement, 6.8% in health and life sciences, 34.4% in research and development, and 44.7% had other professions. After exclusion of the participants who presented at least one missing value in terms of gender, age, educational level and willingness to accept DNA profile insertion in the National Forensic DNA Database, 628 questionnaires were included in our analysis.

Statistical analysis was performed using the Statistical Package for Social Sciences, version 20.0 for *Windows*. Responses are presented as counts and proportions. Acceptance of the individual's own DNA profile insertion in the National Forensic DNA Database according to gender, age and educational level was compared using the chi-square test.

Based on content analysis techniques [32,33], conducted by two independent researchers, the explanations for such decisions were identified and grouped by thematic categories. The construction of the categories emerged from the analysis of the data – it was made *a posteriori* – and followed two steps: first, the researchers systematically compared the concepts contained in each single answer; secondly, the similar concepts were grouped together and formed a category. These categories were then summarized in four main types: the "law-abiding citizen" who includes answers where the distinction between being a criminal and a non-criminal was emphasized; "regulation and human rights", where the reasons were related to concerns about equality, access, control and privacy; "societal benefits", when answers pointed out the advantages of DNA databases for society and for the individuals; and "other reasons". The specific views included in all of these four types of answers are identified in Table 2. An almost perfect strengthening of agreement was achieved, and disagreements in classification were discussed and resolved by consensus.

The study protocol related to the methods for collecting and processing the obtained data, and for assuring anonymity,