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

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 analyse 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 voluntarily 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.

Key-words: forensic science; forensic genetics; DNA databases; public attitudes.

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 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 [13-16, 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 analyse 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 analyse samples, unidentified corpses, missing persons or their relatives, crime scene stains, formal suspects and persons convicted and sentenced to no fewer than three years 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 or research centers 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 (categorised 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 analyse 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 analysed 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 emphasised; “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, confidentiality and privacy was approved by the Foundation for Science and Technology (Portuguese Ministry of Education and Science) and followed the legal regulations of the Portuguese Authority of Data Protection and the ethical guidance of the Portuguese Sociological Association.

3. Results

The characteristics of the study participants and their willingness to accept inclusion of individual genetic profile in the National Forensic DNA Database are summarized in Table 1. This sample is skewed by the level of education (more than 80% of the respondents hold a university degree, while in Portugal the percentage was 14.8% in 2011). Overall, the participants' mean age was 32 years (range: 17 to 82 years), and almost 70% were female. In this sample of the Portuguese population, 46.5% would accept inclusion of individual genetic profile in the National Forensic

DNA Database, while about one quarter (23.2%) would refuse. Willingness to accept an individual's own DNA profile insertion decreased markedly with age (from 55.2% under 23 to 34.9% upwards 38 years, $p < 0.001$) and education (from 53.2% among those with less than tertiary education to 39.3% among those with the highest levels of education, $p = 0.011$). Men were reported to refuse their DNA profile inclusion more often (27.5% versus 21.4% among women, $p = 0.250$).

Table 1. Willingness to accept inclusion of individual genetic profile in the National Forensic DNA Database, by sex, age group and educational level

	TOTAL n=628 n (%)	Yes n=292 (46.5%)	Perhaps n=190 (30.3%)	No n=146 (23.2%)	p
Gender					
Female	435 (69.3)	207 (47.6)	135 (31.0)	93 (21.4)	0.250
Male	193 (30.7)	85 (44.0)	55 (28.5)	53 (27.5)	
Age (years)					
17-23	143 (22.8)	79 (55.2)	45 (31.5)	19 (13.3)	<0.001
24-30	191 (30.4)	101 (52.9)	46 (24.1)	44 (23.0)	
31-37	119 (18.9)	51 (42.9)	40 (33.6)	28 (23.5)	
≥38	175 (27.9)	61 (34.9)	59 (33.7)	55 (31.4)	
Education level					
Less than tertiary education	109 (17.4)	58 (53.2)	36 (33.0)	15 (13.8)	0.011
Bachelor	280 (44.6)	140 (50.0)	78 (27.9)	62 (22.1)	
Master or Doctoral	239 (38.1)	94 (39.3)	76 (31.8)	69 (28.9)	

The participants who accepted or refused inclusion of their individual genetic profile in the National Forensic DNA Database justified their answers mainly with reasons related to the general category of views that the authors have conceptualized as “law-abiding citizen” (45.9% and 60.3%, respectively), while issues linked with “regulation and human rights” were highlighted by 40.5% of those who were undecided (Table 2). The societal benefits constituted the third group of reasons cited by those who accept (22.9%) or maybe accept (11.1%) being included in the DNA database, arguments that were never used by those who refused it.

The answer “I am not a criminal” proved to have a higher relevance as motive for not accepting (59.6%), followed by concerns about lack of control about the use and access to the database (13.7%), and the perception that the inclusion of individual genetic profiles on the National Forensic DNA Database is a violation of individual

privacy (11.6%). The belief that everyone should be part of the database as a contribution to fighting crime, as well as the opinion of having nothing to hide and nothing to fear, emerged as key explanations for acceptances (sum of these categories, 62.4%).

Being unaware of the type of regulation that is implemented for the uses of genetic data and for access to the National Forensic DNA Database, the opportunity to help in crime fighting, and lack of control of the use and access to the database were the reasons most frequently cited by those who were undecided (sum of these categories, 53.2%). It is noteworthy to mention that 6.8% of the participants who may accept inclusion of their individual genetic profile in the National Forensic DNA Database reported that they needed more information in order to express a more informed opinion.

Table 2. Reasons reported by the participants to accept, maybe accept or refuse inclusion of their individual genetic profile in the National Forensic DNA Database

	TOTAL n=628	Accept n=292	Maybe accept n=190	Refuse n=146
	n (%)	n (%)	n (%)	n (%)
The law-abiding citizen	284 (45.2)	134 (45.9)	62 (32.6)	88 (60.3)
<i>I am not a criminal</i>	107 (17.0)	4 (1.4)	16 (8.4)	87 (59.6)
<i>To help in crime fighting</i>	92 (14.6)	61 (20.9)	31 (16.3)	0 (0.0)
<i>Nothing to hide, nothing to fear</i>	62 (9.9)	53 (18.2)	9 (4.7)	0 (0.0)
<i>It is a citizen's duty [to give a sample]</i>	22 (3.5)	16 (5.5)	6 (3.2)	0 (0.0)
Regulation and human rights	186 (29.6)	70 (24.0)	77 (40.5)	39 (26.7)
<i>Everyone should be in the database</i>	71 (11.3)	68 (23.3)	3 (1.6)	0 (0.0)
<i>It depends on the sort of regulation</i>	53 (8.4)	2 (0.7)	48 (25.3)	3 (2.1)
<i>Lack of control on the use and access</i>	42 (6.7)	0 (0.0)	22 (11.6)	20 (13.7)
<i>It is a violation of my privacy</i>	21 (3.3)	0 (0.0)	4 (2.1)	17 (11.6)
Societal benefits	88 (14.0)	67 (22.9)	21 (11.1)	0 (0.0)
<i>For my own and society's protection</i>	31 (4.9)	23 (7.9)	8 (4.2)	0 (0.0)
<i>To have a more accurate justice system</i>	28 (4.5)	23 (7.9)	5 (2.6)	0 (0.0)
<i>Useful for criminal and civil identification</i>	24 (3.8)	17 (5.8)	7 (3.7)	0 (0.0)
<i>For scientific research</i>	5 (0.8)	4 (1.4)	1 (0.5)	0 (0.0)
Other reasons	34 (5.4)	4 (1.4)	18 (9.5)	12 (8.2)
<i>I need more information</i>	16 (2.5)	1 (0.3)	13 (6.8)	2 (1.4)
<i>Faulty uses in criminal justice</i>	7 (1.1)	0 (0.0)	2 (1.1)	5 (3.4)
<i>It is useless</i>	7 (1.1)	0 (0.0)	2 (1.1)	5 (3.4)
<i>It is the same as fingerprinting</i>	4 (0.6)	3 (1.0)	1 (0.5)	0 (0.0)
No answer	36 (5.7)	17 (5.8)	12 (6.3)	7 (4.8)

4. Discussion

The explanations regarding willingness to accept the individual's own DNA profile insertion in the Portuguese National Forensic DNA Database indicate awareness of the crime-solving potential of forensic genetics and show tensions in the assessment of the benefits and risks of such action. The potential benefits and risks of a National Forensic DNA Database are judged in relation to collective concerns for the well-being of society in general, but the main reasons presented for accepting or refusing the inclusion of the individual's genetic profile are related to the self-reflecting evaluation of someone's being a criminal or not.

The respondents who accepted having their profile included tended to justify their answers on the basis of the argument that the DNA technologies are very useful, both to identify criminals and to society as a whole. This assessment was expressed by answers like the more abstract assumptions that it would "help in crime fighting" or "Nothing to hide, nothing to fear" to the more concrete suggestion that "Everyone should be in the database". The overriding willingness to accept the inclusion of the individual genetic profile indicates the acknowledgement of the investigative potential of forensic DNA technologies and a relegation of human rights and civil liberties to the background, because of the perceived benefits of protecting both society in general, as well as to assure the individual's own protection. These reasons were also found in the analysis conducted by Wilson-Kovacs and others [21] of the data obtained in the UK in the Spring 2006 Mass Observation Directive "Genes, Genetics and Cloning". This might suggest that the tendency to prioritize the protection of the social body and the individual's self-protection against crime, and the willingness to contribute to that double purpose, have a cross-cultural and transnational character, rather than being associated only with national idiosyncrasies.

Previous research aimed at analysing public attitudes and opinions towards forensic DNA databases indicates that there are shared concerns and homogeneity in the perceptions about certain topics, which are contextually and historically bound, and reveals the existence of a common body of knowledge about the ethical, legal and social issues related to DNA databases [23, 24]. Specialists and the 'lay' public tend to have similar responses related to concerns about unforeseen uses or access given to parties not involved in criminal investigation or those with commercial interests [25]. Surveys carried out in the general population in different national contexts revealed consensus in the previously mentioned issues: the support for the inclusion of DNA profiles of convicted violent offenders [26, 27]; the belief that forensic DNA

databases are a powerful tool for re-establishing public trust in the criminal justice system [13]; and the assumption that DNA evidence is a provider of absolute and irrefutable truth [21].

On the basis of similar reasoning related to the dichotomy of being a criminal/non-criminal, but emphasising the concerns about the risks of accepting the inclusion of the individual genetic profile in the National Forensic DNA Database, the individuals who refused explained their motives by resorting to the formulation “I am not a criminal” and by referring to lack of control and insufficient or unclear regulations related to safeguarding individuals’ data and supervising the access and uses of genetic data. Although concerns about the possible abuse or lack of control of the access to information included in the DNA databases may also have a cross-cultural nature, the perceived risks expressed by our respondents may also reflect the fact that in Portugal public confidence in politics, business, police and the judiciary is weak compared to most European countries [34].

Nevertheless, about 11% of the participants explained their choice to accept having their profile in the National Forensic DNA Database by answering that “Everyone should be in the database”. It is relevant to take into consideration that in another question of the questionnaire, more than one-third of the participants (36.0%) agreed with the statement “Any person should be in the criminal DNA database”. The acceptance of the creation of a universal database was found in a study carried out in South Wales [29], and in a study with male prisoners in Portugal [35]. This relative support for the creation of a universal database may be explained by the citizen’s passive compliance with the states’ requirements for collecting diverse personal identification data [36].

A stratified survey of the Spanish population indicated homogeneity among the answers to the question about the persons or institutions that may have access to data of individuals, but also an association between educational level, profession and age and the views on the regulation and ethical impact of DNA databasing [26, 28]. For instance, participants working in the field of law showed less support for a National Forensic DNA Database for all citizens than professionals involved in the health sector and in local and national security and law enforcement [26, p. 601]; older and younger participants (more than 65 or between 15 and 24 years, respectively) were those who most frequently agreed with the transferring of data from DNA profile databases to Local and State Security Agencies [28, p. 143]; and awareness of the use

of DNA profiling in the identification of persons increased markedly with education [28, p. 144].

Consultations on the public views on DNA-related matters, and more specifically in relation to the UK National Criminal Intelligence DNA Database NDNAD, have been made on a systematic basis in this country, presenting somewhat ambivalent results. The Wales 2007 Gene Park and Techniquet public discussion found that 60% of the participants favoured a universal DNA database and indefinite DNA sample retention regardless of whether individuals have been found guilty of an offense [29]. In contrast, public consultations organized by the Human Genetics Commission in the UK suggested that different sectors of the public share concerns about the potential access by employers, insurance or commercial companies and other unforeseen uses, and expressed lack of enthusiasm for universal database and international data-sharing [21 p. 287; 30, 31]. The Spring 2006 Mass Observation Directive “Genes, Genetics and Cloning” showed continuities and tensions between the appreciation of the benefits of using DNA identification techniques in police work and a more critical attitude towards a wider national DNA database [21].

The complexity and ambivalence of public views about forensic DNA databases and forensic DNA technologies indicate that there is a need to do more research exploring the finer details of interpretation of the risks and benefits of forensic genetic technologies [21]. As suggested by Jasanoff [37], the ethical issues of genetic technologies, and the potential public benefits of their uses need to be questioned and re-examined on the basis of a multi-vocal approach to views about the benefits and risks of forensic DNA technologies – one that also involves citizens – serving as a resource for a better understanding of individual perspectives and collective attitudes. Although our questionnaire was applied to a non-representative sample of the Portuguese population, and this convenience sample lacks the generalizability of a random sample, this study may indicate the general attitude of Portuguese people with higher levels of education. While the limitations of the study need to be addressed, it contributes to an empirically-grounded understanding of the willingness to donate voluntarily a sample for profiling and inclusion in a National Forensic DNA Database. These collective views also relate to the perceived utility and risks of operating forensic DNA databases. In alignment with the larger project on social and ethical aspects of forensic DNA databasing in Portugal that sustains this study, we argue for the need for a deeper awareness of the ethical complexities surrounding the

criteria for collection and insertion of DNA profiles in forensic databases in Europe and beyond. Possible and desirable routes should be built for effective public engagement that can account for the heterogeneity of knowledge and expectations, and certainties and uncertainties raised by forensic DNA databases. From our point of view, the accomplishment of this goal demands broader research on the public understanding of the role of highly advanced technology in crime fighting that provides more in-depth data to document collective views on the development and governance of DNA databasing. By representing the perspectives and attitudes of the public, this study could be useful for the development of international common ethical standards for the content and use of DNA databases to ensure that the potential of forensic DNA databases to fight crime is well explored in a framework in which human rights are respected.

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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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