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Promotion and protection of all human rights, civil,
political, economic, social and cultural rights,
including the right to development

Report of the Office of the United Nations High Commissioner for Human Rights on the right to the truth and on forensic genetics and human rights*

Summary

The present report is submitted pursuant to resolutions 9/11 and 10/26 of the Human Rights Council, in which the Council requested the Office of the United Nations High Commissioner for Human Rights “to prepare a report, to be presented to the Council at its fifteenth session, on the use of forensic experts in case of gross violations of human rights with a view to identifying trends and best practices in this regard” and “to request information from States, intergovernmental and non-governmental organizations on best practices in the use of forensic genetics for identifying victims of serious violations of human rights and international humanitarian law with a view to considering the possibility of drafting a manual that may serve as a guide for the application of forensic genetics, including, where appropriate, the voluntary creation and operation of genetic banks, with appropriate safeguards”.

In response to a note verbale from the Office of the High Commissioner dated 8 February 2010, information was received from Argentina, Colombia, Cuba, El Salvador, Hungary, Japan, Jordan, Mali, Mauritius, Mexico, Oman, Peru, Portugal, Romania, Slovakia, Spain, Tunisia and Turkmenistan. The report also benefitted from the contributions and analysis of the Argentine Forensic Anthropology Team (EAAF), and the International Commission on Missing Persons (ICMP) which coordinated for the purpose of this report the contributions of the DNA working group of the European Network of Forensic Science Institutes, the DNA Commission of the International Society for Forensic

* Late submission.

Genetics (ISFG), contributors involved in the establishment of the AABB Guidelines for Mass Fatality DNA Identification Operations, representatives of the Missing Persons Committee of the United States of America Scientific Working Group on DNA Analysis Methods, representatives of the Alliance of Forensic Scientists for Human Rights and Humanitarian Investigations, the International Forensic Program of Physicians for Human Rights and, the members of the Steering Committee on Forensic Science Programs (SCFS) at the ICMP.

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I. Introduction

1. As indicated by the Government of Argentina in its response to the note verbale sent by the Office of the United Nations High Commissioner for Human Rights (OHCHR), the Human Rights Council aimed to achieve three main objectives in its resolutions concerning forensic genetics and human rights:

(a) To recognize the importance, and promote the use, of forensic genetics as a key tool of forensic sciences in situations where there have been violations of human rights and international humanitarian law. Such recognition on the part of the international community would better promote the use of scientific advances and the encouraging results achieved at the national and regional level with a view to resolving similar situations in other parts of the world;

(b) To promote enhanced cooperation between States and organizations in the use of forensic sciences in general and forensic genetics in particular in the investigation of such violations, greater international cooperation to promote exchange of information between States and organizations with relevant experience in this area which would facilitate identification and help locate victims' relatives who have moved away from their places of origin and need to be contacted;

(c) To promote the development of international standards on the use of forensic genetics. The existence of a model protocol or internationally approved manual would ensure that national genetic databanks apply methodologies that are accepted by the scientific community and that they abide by those legal principles that are essential for ensuring the non-partisan nature of their work and the protection and confidentiality of the data and outcome information, and for restricting access thereto.

II. The use of forensic experts in cases of gross violations of human rights

2. Forensic science is concerned with establishing facts, obtained through scientific means, which will be introduced as part of a criminal investigation as evidence in court, most commonly for the purpose of prosecuting crimes. It is also used, inter alia, to identify missing persons as a result of human rights violations or from multiple fatalities resulting from natural disasters. Forensic science is, therefore, one of the enabling tools to ensure the full implementation of the rule of law, and as such it needs to conform to the rule of law itself.

3. In a national context the application of forensic science is regulated by legislation and detailed domestic legal frameworks or domestically accepted practices that seek to ensure such conformity. At the international level, however, the rules and acceptable practices are often less clear, sometimes contradictory, or even absent altogether. That situation is rapidly changing due to an ever-increasing reliance on forensic methods and techniques, both domestically and across national borders.

A. Examples of national practices on the use of forensic experts in cases of gross violations of human rights

4. In Argentina for example, the Office of the Secretary for Human Rights of the Ministry of Justice, Security and Human Rights has created the "Register of unidentified skeletal remains of disappeared detainees". The purpose of the initiative is to put together

all the available information in Argentina regarding the current condition of the skeletal remains of exhumed corpses, corresponding to excavations carried out with the aim of locating persons who disappeared during the military dictatorship.

5. One of the aims of the Register is to establish an inventory of the previously found or newly unearthed skeletal remains that are known to be, or are allegedly, those of disappeared persons who were victims of the illegal repression carried out by State terrorism, but who have yet to be identified, or whose relatives are not known. A further, parallel aim is to create a database in which this information can be classified and systematically ordered.

6. In Spain, the forensic community provides expert services at the request of the courts and may only intervene in open cases, unless a court order is issued. This situation does not restrict the experts' activities, since they provide their reports to the relevant court, whether at the behest of the judicial authorities or any of the parties involved in the case. The fact that the forensic community has freedom to act with complete independence, to the best of its knowledge and belief, makes it a key instrument in building cases against persons. This approach to reporting is not confined to living persons and can also be applied to the recently deceased and even to less recent deaths.

7. The forensic community refreshes and updates its knowledge base through continuous training, which forms the cornerstone of the community's work and involves constant contact with scientific experts, which has led it to engage in a series of activities both within Spain and abroad. This manner of conducting expert work, in this case in the area of human rights, is no accident, but the result of a series of action plans relating to forensic activities, which now reflect best practices in that field.

8. The Ministry of Justice has worked with the Centre for Legal Studies to develop a procedure for the training of forensic experts, which includes the following: (a) training courses; (b) protocols for procedures to be followed; (c) professional seminars; and (d) comprehensive forensics management tools.

9. In Peru, the Institute of Forensic Medicine of the Attorney-General's Office comprises a group of experienced forensic experts with a variety of specializations. The experts are responsible for intervening in cases involving serious human rights violations and are members of the Specialized Forensic Team (EFE). They are responsible for searching for, recovering and analysing the remains and related personal effects of persons who have disappeared in circumstances characterized as serious violations of human rights.

10. The Institute of Forensic Medicine is currently standardizing the methodologies used to search for, recover and analyse the remains of disappeared persons, not only in circumstances characterized by serious violations of human rights but also in so-called ordinary circumstances.

11. Given that the cases solved by the Specialized Forensic Team (EFE) are of national importance, it reports directly to the national headquarters of the Institute of Forensic Medicine. This enables the Institute to respond promptly to requests from any prosecutor specialized in human rights at the national level. EFE never acts alone unless it is asked to do so by a prosecutor specialized in human rights law. As such, EFE works in coordination and conjunction with the prosecutor in charge of any given investigation.

12. In Portugal, it is the Instituto Nacional de Medicina Legal which has the legal competence to perform forensic examinations within the national territory. The Institute is autonomous and independent, fulfils the international requirements on forensic genetic examinations, and has applied for many years the quality controls promoted by the International Society for Forensic Genetics. The Institute also gives judicial support and has representation in the European DNA Profiling Group.

B. General considerations in the use of forensic experts in cases of gross violations of human rights

13. It is to be noted that the use of forensic experts in cases of gross violations of human rights implies several prerequisites, which can contribute to guaranteeing the credibility of such processes. In particular with regard to exhumation and identification processes, it is proposed that only once a framework has been agreed upon by all those concerned, can these processes begin. In this regard, it is suggested that the framework should include:

(a) The establishment of protocols for exhumation, ante mortem data collection, autopsies and identification based on scientifically valid and reliable methods and technologies and/or customary, clinical or circumstantial evidence that are deemed appropriate and which have been previously adopted by the scientific community;

(b) Appropriate means of involving the communities and families concerned in the exhumation, autopsy and identification procedures;

(c) Procedures for handing over the human remains to the family.

14. It should also be mentioned that in many parts of the world, the use of forensic science in investigating human rights violations is still not standard practice. Although the technological gap in the area of forensics has decreased over the last two decades in some regions that have less technological capability, the credibility of official forensic institutions continues to be a major issue. Upgrading equipment and providing training is crucial to improving results and credibility.

15. While there has also been some improvement in this area, it remains critically important, but extremely difficult, to carry out independent forensic investigations or for independent experts to accompany forensic officials investigating human rights violations. Forensic investigations that are conducted solely by potentially unprofessional experts or institutions, which may have conflicts of interest, often do not provide satisfaction to families of victims and society as a whole, resulting in additional requests for further investigation.

16. Training and promoting local forensic experts is also an important issue. While the major contribution made by the international forensic teams who assisted in the search for those person who went missing or disappeared as a result of wars, internal conflicts and repressive regimes has been recognized, it is also important that they do not limit their intervention to forensic investigation and analysis, but also extend it to working with, training, and promoting local teams of forensic experts. This issue is essential for a variety of reasons:

(a) In some countries, the forensic work of identifying victims of violations takes a long time. International teams will usually spend only a limited amount of time during each mission, and only for a few years, while a national team can dedicate itself full-time to this work until the case is concluded;

(b) In many countries, forensic sciences are less developed or almost non-existent and in most cases the use of archaeological, anthropological and genetic techniques is uncommon or absent. The use of physical evidence in court is, in general, limited and testimony is usually provided orally. Therefore, by training or creating a national forensic team or forensic professionals who can address this problem, there will usually be a general improvement in criminal procedures and, as a result, in the implementation of the rule of law;

(c) National teams may serve the families of the victims and their communities in more effective ways, as they speak the same language, are from the same or a similar

culture, have often lived through similar experiences, and often have a strong commitment to improving the human rights situation and the rule of law in their own countries.

17. The Colombian Government additionally recommended that the following points be taken into account in all processes intended to identify victims of human rights violations and violations of international humanitarian law:

(a) Investigations should be comprehensive in the sense that they should not only focus on the reliable identification of corpses but also on the circumstances that led to those persons' deaths;

(b) Teams of highly trained specialist investigators should be able to work under stable conditions alongside specialists in other disciplines;

(c) The information generated in the course of different operations should be handled in a coordinated manner to enable case monitoring, consultation and cross-referencing of the data, and consequently better handling of investigations, especially when there are overlaps between similar investigations. This can be achieved using a single software programme for all offices operating in all parts of the country, with restricted access rights and correspondingly enhanced security;

(d) Reliable identification processes should be handled in a coordinated manner with the involvement of an interdisciplinary team made up of, inter alia, pathologists, forensic medical specialists, radiologists, anthropologists, odontologists, fingerprint experts, photographers, morphologists and forensic geneticists, thereby enhancing the efficiency of the decision-making process regarding the types of analyses to be carried out, depending on the investigation, the background to the investigation and the discoveries made, until a reliable identification can be finalized;

(e) Proper handling of samples for genetic testing must be ensured from the moment they are collected from the scene. For this purpose:

(i) All of the sampling processes must be fully documented, with clear and detailed instructions for the persons responsible for such activities, unified records covering the entire country must be kept, and sampling kits made available;

(ii) A single coding system should be used for all samples;

(iii) Relatives of the victims should be interviewed to obtain all necessary information on the whereabouts and availability of their closest blood relatives for the purpose of finding genetic matches or obtaining information on other sample types, such as personal belongings, biopsies and biological tissue samples that can be recovered and used to identify victims;

(iv) There should be a documented procedure for collecting samples from victims' relatives, including kits comprising all the materials required for this purpose, namely instructions both for sampling staff and for relatives written in clear, concise and factual language, explaining what genetic analysis involves, what the possible results are, where to go for information or advice, and how to complete informed consent forms to comply with bioethics standards;

(v) Information systematization tools should be provided to ensure better tracking of samples, procedures and results in all participating laboratories;

(vi) Information should be made available on key discoveries and exhumations, including information on the number of bodies recovered, the type of grave (primary or secondary), any soil characteristics that might affect the outcome of the genetic analysis, and the general condition of the remains recovered, as well as an indication

of whether or not a body was found whole, whether a potential identity is known, whether the victims included blood relatives and if so how they were related, etc.

III. Forensic genetics and human rights

A. Practices at the national level in the use of forensic genetics for identifying victims of serious violations of international human rights and humanitarian law and the voluntary creation of genetic databanks

18. In Argentina an agreement has been signed with the Argentine Forensic Anthropology Team (EAAF), through the Ministry of Health and the National Memory Archives attached to the Office of the Secretary for Human Rights, with the aim of implementing and supporting the “Latin American initiative for the identification of disappeared persons” in Argentina. This initiative is intended to achieve a significant increase, at the regional and local level, in identifications of the remains of victims of politically motivated enforced disappearances in Latin America. At the local level, the agreement involves collecting blood samples in order to carry out large-scale DNA tests, the results of which are added to archives operating under the umbrella of the National Memory Archives and managed jointly by representatives of the Archives and EAAF.

19. The agreement includes a confidentiality clause binding on all parties and intended to protect donors by requiring their informed consent. Donors in turn have the right to access the genetic information resulting from processing of the samples. Only EAAF and the Office of the Secretary for Human Rights have access to the samples deposited in the genetic databank. The two agencies have signed a confidentiality agreement with the Ministry of Health, and another has been signed by EAAF and the genetic laboratories that analyse the samples. The information generated by the analyses is strictly confidential.

20. The genetic tests carried out on the blood samples involves comparing the genetic profiles of the blood with the genetic profiles of a bone sample taken from the remains of possible family members. The entire process is completely free of charge for family members. It should also be noted that a blood sampling system has been set up in various countries through the Argentine Ministry of Foreign Affairs, International Trade and Worship.

21. In establishing the National Genetic Data Bank by Act No. 23.511 of 13 May 1987, Argentina reaffirmed its commitment to seek by any and all means information on the whereabouts of children who had been abducted with their parents or born during their mothers’ captivity, and who had been taken away and given new identities by persons directly or indirectly associated with State terrorism. The National Genetic Data Bank made it possible to identify with scientific certainty 101 children who had been abducted and given new identities, and to restore their identity and personal history.

22. Government policy was further reinforced in November 1992 when, pursuant to Act No. 25.547, the national executive set up the National Commission on the Right to an Identity (CONADI), and thereby established a working relationship between NGOs and the State. The primary purpose of CONADI is to guarantee the right to an identity and to lead the search for children who disappeared during the military dictatorship. Anyone born between 1976 and 1983 who has doubts about his/her identity or believes they may be the children of persons who disappeared during the last military dictatorship can seek the assistance of CONADI to open a case file for an investigation into their biological origin, without having to initiate court proceedings. If deemed necessary, CONADI can perform DNA tests for free, in cooperation with the National Genetic Data Bank.

23. In 2004, the national executive set up a special unit to investigate the disappearance of children as a result of acts of State terrorism. The unit provides assistance in cases involving such disappearances and is authorized to launch its own investigations, in which case the results must be transmitted to the judicial authorities.

24. A bill sent to Congress in September 2009 by the national executive proposed certain changes in the operations and scope of the National Genetic Data Bank with a view to developing more effective mechanisms for facilitating the identification of the children of the disappeared. As a result, on 18 November 2009, Congress adopted Act No. 26.548 on the National Genetic Data Bank. According to article 2 of the Act, the Bank aims “to ensure the collection, storage and analysis of the genetic information required as evidence for the elucidation of crimes against humanity instigated in national territory up to 10 December 1983, and to facilitate (a) the search for and identification of the sons and/or daughters of the disappeared who were abducted with their parents or born during their mothers’ captivity, and (b) the genetic identification of the remains of victims of enforced disappearances”.

25. The Act ensures the protection of the data and information in the Archive, in compliance with legislation on the protection of personal data and personal privacy, and guarantees that experts’ reports are checked by technical consultants who may be appointed by the parties to court proceedings.

26. With regard to El Salvador, the Inter-American Court of Human Rights, in its ruling in the case of the *Serrano Cruz Sisters v. El Salvador*, ordered the State to create a system that “allows genetic data that can contribute to determining and clarifying the relationships and identification of the disappeared children and their next of kin to be obtained and conserved.”¹

27. The current Government of El Salvador, through the Ministry of Foreign Affairs, has prioritized compliance with the recommendations of international systems for the protection of human rights and has, inter alia, committed itself to building a genetic information system for the identification of children who disappeared during the internal armed conflict, with a view to converting it into a genetic information system with a broader mandate covering the identification of victims of serious violations of human rights during the internal armed conflict, as well as present-day victims of violence. Another aim of the new Government is to contribute to strengthening State scientific capacities in the area of forensic investigation, including forensic genetics. This is consistent with the interest expressed by the current judges of the Supreme Court of Justice of El Salvador, to whose authority the Institute of Forensic Medicine is subordinated.

28. Regarding the issue of genetic databanks in Colombia, it should be noted that, in 2003, within the framework of the Plan Colombia programme, CODIS (Combined DNA Index System) was donated to Colombia by the Department of State of the United States through the International Criminal Investigative Training Assistance Program (ICITAP), with the aim of supporting judicial investigations mainly of offences known to have a high rate of recidivism. CODIS is a computer system that stores DNA profiles in a database so that they can be matched with persons suspected of committing an offence.

29. The database is placed under the supervision of the Inter-institutional Subcommittee on Genetics. The Subcommittee defined the database as a “national database of genetic profiles for use in judicial investigations”, decided on its internal operations, access restrictions and use, developed a user manual, and established a variety of categories for the storage of genetic profiles, namely:

¹ See http://www.crin.org/docs/FileManager/IAC_El_SalvadorForced%20disappearance.doc.

- Index
- Evidence recovered from crime scenes
- Convicted
- Human remains of disappeared persons
- Relatives of disappeared persons.

30. The national database of genetic profiles for use in judicial investigations has all of the safeguards required to guarantee the following: the information and records are confidential; storage, access and use are restricted; the chain of custody of the samples is controlled in accordance with the legislation currently in force; data are disaggregated, meaning that unique codes are assigned to each processed sample and entered into the database; the genetic information obtained from the samples is used only for identification purposes; queries are answered only by the competent authorities; and sample collection is carried out in full compliance with fundamental rights and due process as per the legislation currently in force, with informed consent consistent with bioethics regulations governing studies carried out on human beings.

B. Framing the context and primary components of a text on forensic genetics and human rights

31. The past two decades have shown the clear limits of trying to identify the remains of victims of human rights violations or missing persons from internal conflicts or wars, using only background, medical and dental ante-mortem records. In this sense, forensic genetics have a crucial role to play, drastically increasing the possibility of identifying many more remains and thus providing solace to families of victims and evidence to ongoing and/or future prosecutions.

32. Advances in technology have allowed large-scale genetic projects aimed at identifying victims of human rights violations to be conducted.

33. Creating databanks of relatives of disappeared people is crucial to conducting large-scale identification projects that can take place simultaneously or in the future. The more complete the databank of relatives of victims, the greater the chance of identifying remains that are found and are thought to correspond to a victim of a human rights violation or a missing person from a conflict.

34. Creating such databanks will also enable identifications in the future, as more grave sites are discovered, whether or not information from all relatives is available. Having the support of associations of relatives of disappeared and missing people is also crucial.

35. Establishing a genetic databank also requires clear provisions about, for example, its goals, restrictions in use, expectations, consent, confidentiality, and procedures to be used. Consequently, the goals and limitations need to be very clear when creating a genetic databank of relatives of disappeared and missing victims, and must be publicly stated from the start. The goal of such databanks, for example according to EAAF, need to be strictly limited to the identification of remains of victims of specific events, which should be outlined from the start. Any further use - even scientific use of the genetic data or samples not related to identification purposes - should not be permitted or should require the written consent of the sample donors. Commercial use of genetic information should never be part of the goals of such databanks.

36. Databanks should also establish whether they will only collect samples or will also process them and compare them with genetic information from victims' remains. In other

words, setting up a databank is only the beginning of a long road in the identification process. The donation of samples should be voluntary and forms explaining the project, its limitations, the restrictions in use of the samples, and confidentiality of the donor, among other clauses, should be provided to donors before their donation of a sample. Databanks should set up standard operating procedures for the collection of samples, and in particular:

- (a) Control and assessment mechanisms when collecting samples from the target population. In any society there are missing people, but they are not necessarily the ones targeted by the creation of the bank;
- (b) Controls so that blood or saliva is correctly taken, with no contamination involved;
- (c) Use of codes or bar codes to protect confidentiality of the victims;
- (d) Controls for storage and transport that ensure the chain of custody.

37. Databanks should have a board, on which sit not only officials and forensic scientists, but also representatives of associations of relatives of disappeared or missing people. This is critical to guarantee that their concerns are accounted for and to avoid political manipulation or other deviations from the founding principles of the databank.

38. Confidentiality is essential and possible by using bar codes to identify the samples of both relatives and victims. Only the donors of the samples, the board of directors of the databank and the designated official and/or judicial bodies should have access to this information.

39. The plan and limitations of databanks need to be explained to the general public, particularly to relatives of victims, before they donate a blood or saliva sample. External periodic audit of databanks by internationally recognized institutions, such as the International Committee of the Red Cross, are recommended. Families of victims also have the right to be informed of the limits of the project.

40. The credibility of the scientists or institutions processing the samples and the custodians of the databank is critical for the success of the project, as trust in State institutions, including forensic systems, have often broken down in human rights cases.

41. The identification process needs a multidisciplinary approach, which starts with the proper recovery and documentation of the remains, and the associated evidence, and their anthropological analysis. Background information on each case and the correct collection of family samples is also crucial. Geneticists work in constant collaboration and exchange of information with anthropologist, archaeologists, and investigators, producing one final multidisciplinary identification report.

42. The International Commission on Missing Persons (ICMP) for its part has previously been involved in discussions on developing practical guidelines based on its extensive experience in identification efforts on disaster human rights victims. It has, for the purpose of the present report, been in consultation with specialized organizations and prominent individuals in the field of forensic genetics to discuss, inter alia, the potential merits of a United Nations sponsored manual on this matter. These organizations include the DNA Working Group of the European Network of Forensic Science Institutes; the DNA Commission of the International Society for Forensic Genetics (ISFG) that authored the "Recommendations regarding the role of forensic genetics for disaster victim identification (DVI)"; contributors involved in the establishment of the AABB Guidelines for Mass Fatality DNA Identification Operations; representatives of the Missing Persons Committee of the United States Scientific Working Group on DNA Analysis Methods; representatives of the Alliance of Forensic Scientists for Human Rights and Humanitarian Investigations;

the International Forensic Program of Physicians for Human Rights; and the members of the Steering Committee on Forensic Science Programs (SCFS) at the ICMP.

43. These interlocutors and ICMP are unanimous in support of the Human Rights Council examining the application of forensic genetics to human rights, and recognizing the benefit of guidelines that could aid governments and other actors in formulating approaches to identification in human rights contexts that are appropriately grounded in scientific methodology. It is important to note that forensic genetics is the most rigorously established scientific basis for identification, and the international community should seek mechanisms by which this tool can be used to maximum benefit.

44. With regard to the establishment of a United Nations manual on the use of forensic genetics, ICMP suggested that it would be both difficult and redundant to produce and maintain a manual that addresses the use of forensic genetics in any technical specificity. Given the pace of technical development in the field, and the range of technical approaches that can be brought to bear, it would be excessively burdensome to maintain technical recommendations that keep pace with evolving guidelines from professional organizations that frame technical approaches and practical considerations, and define quality assurance standards or best practices.

45. However, it would be useful if a set of United Nations guidelines were to: (a) raise awareness of forensic genetics as enabling governments to comply with human rights obligations, in particular but not exclusively in the context of missing persons; and (b) refer to the requirement that such efforts be based on objective scientific methods to the maximum extent possible. With regard to the application of forensic genetics, the guidelines could also emphasize best practices in the field with regard to such issues as laboratory accreditation, formal quality assurance mechanisms, training and certification of analysts. A set of United Nations guidelines established in consultation with the practising community of forensic genetic scientists would certainly be of considerable value.

46. An area of high importance and value for such guidelines would be the issues of genetic data protection and informed consent. The issues of genetic sample and database access and retention, and the fact that forensic genetic investigations can reveal unexpected family relationships, call for a set of guiding principles that are substantially lacking in the field. The Human Rights Council is very well positioned to address such underdeveloped areas.

47. In its contribution to the present report, Turkmenistan stated that the increased use of forensic genetics to identify victims of violations of human rights and humanitarian law and the establishment of a genetic databank would make a significant contribution to establishing the truth and protecting human rights in judicial proceedings. For this reason, Turkmenistan is exploring the possibility, with the support of the Academy of Sciences and the law enforcement agencies, of establishing laboratories to carry out forensic genetic investigations and subsequently also of setting up a genetic databank.

C. The existing human rights legal framework

48. Given the benefit and utility of forensic science in enabling governments to fulfil their obligations in national and international settings, its use must be commensurate with human rights standards. Meanwhile, some existing international legal instruments that address the use of genetics in the context of medical research generally exempt its forensic applications from their purview. A notable exception is Human Rights Council Resolution 10/26 on forensic genetics and human rights that urges governments to apply forensic genetics pursuant to international standards accepted by the scientific community in identifying the remains of victims of serious violations of human rights and of international

humanitarian law. International standards pertaining to the use of forensic science are not unified. It is necessary, therefore, to further analyse the impact on human rights of the use of forensics and especially forensic genetics more generally, outside the crime prevention context.

49. Human Rights Council resolution 10/26 appropriately attributes the competency for the development of adequate standards for the exercise of forensics to the relevant scientific community. Nevertheless, the exercise of forensic science needs to be scrutinized not only within the scientific community with a view to applicable scientific standards and practice, but also to its impact on human rights.

Jurisprudence

50. While the development of forensic science has significantly enhanced the capabilities of governments to fulfil, inter alia, their human rights obligations, if applied without appropriate regulatory standards, it has the potential to trump individual rights. One recent court decision, for instance, demonstrates just how the application of forensic science impacts individual rights in the criminal law context. In the case of *S. and Marper v. the United Kingdom*² the European Court of Human Rights held that the application of forensic science and in particular forensic genetics needs to conform to human rights standards, as enshrined in the European Convention on Human Rights (ECHR).

International instruments

51. The International Convention for the Protection of All Persons from Enforced Disappearance sets out, inter alia, the use to which personal information can be put in the case of such disappearance; the duties of States parties in relation to the victims of enforced disappearance, including children who are victims themselves or are the children of victims; and the right of victims to know the truth about the circumstances of enforced disappearance, and the progress and results of any investigation.

52. Four other international legal instruments also address a number of ethical issues that are becoming increasingly apparent due to the rapid development of genetic science and its various applications. The intrusion on private life and the right to information are the areas most affected by these developments. While in a number of cases the concern was the legality of an infringement on rights without the consent of the person concerned, many applications of forensic genetics, for example in identifying missing persons in post-conflict and disaster situations, are being conducted through the voluntary participation of individuals, such as relatives. The only way to legitimize the intrusive application of genetic science, in such a context, is through the informed consent of the potential data subjects.

53. The Convention on Human Rights and Biomedicine (Oviedo Convention, 1997) stipulates the major principles on which subsequent instruments dealing with the topic continue to build. It provides a common framework for the protection of human rights and human dignity in both long-standing and developing areas concerning the application of biology and medicine.³ The Convention affirms a well-established rule that no one can be forced to undergo a medical intervention without his/her consent. Consent has to be free and informed and given on the basis of objective information from the responsible health-care professional as to the nature and the potential consequences of the planned intervention or of its alternatives, in the absence of any pressure from anyone.

² *S and Marper v. the United Kingdom* (App. No. 30562/04) [2008] ECHR 1581 (4 December 2008)

³ Explanatory report on the Convention on Human Rights and Biomedicine available at <http://conventions.coe.int/treaty/en/Reports/Html/164.htm>.

54. Consent, together with the relevant data, may be freely withdrawn at any time. Further, the Convention states that everyone has the right to respect for their private life in relation to information about his or her health.⁴ A few restrictions to rights and protective provisions are permitted to advance collective interests (public safety, the prevention of crime, and the protection of public health) or the rights or freedoms of others.⁵ To be admissible, restrictions must be prescribed by law and be necessary in a democratic society for the protection of the collective interest in question or for the protection of individual interests.⁶ By definition, given its subject matter (interventions in the health field), the Oviedo Convention does not address forensic applications. However, it can provide guidance in cases of consensual forensic genetic testing, such as identifying disaster victims.

55. The United Nations Educational, Scientific and Cultural Organization (UNESCO) Universal Declaration on the Human Genome and Human Rights (1997) recognizes the benefits that research on the human genome adds to humankind as a whole, and underlines that such research should fully respect human dignity, freedom and human rights. It addresses States and seeks to foster international cooperation with developing countries in disseminating scientific knowledge on the human genome, human diversity and genetic research. The Declaration is concerned with genetic treatment, diagnosis and research, with an accent on respecting human dignity through a requirement of consent. The declaration stipulates that individuals have the right to decide whether or not to be informed of the results of genetic examination and the resulting consequences, but it is silent on the right to withdraw personal data once it has been consensually provided. In addition, the Declaration mentions that genetic data that can be associated with an identifiable person must be held confidential according to the law.⁷ Limitations on consent and confidentiality can be imposed only to protect human rights and fundamental freedoms and must be prescribed by law for compelling reasons, consistent with public international law and international human rights law.⁸

56. In response to fears that human genetic data will be used for purposes contrary to human rights and freedoms, the UNESCO International Declaration on Human Genetic Data (2003) stipulates in its preamble that the interests and welfare of the individual should have priority over the rights and interests of society and research. It sets out a number of rules for the collection, use and storage of human genetic data. It covers, among other issues, informed consent in genetics; confidentiality of genetic data; genetic discrimination; anonymity of personal genetic information; population-based genetic studies; the right not to know one's genetic make-up; international solidarity in genetic research, and benefit sharing. The Declaration clearly states that it aims to ensure respect for human dignity and the protection of human rights and fundamental freedoms in the collection, processing, use and storage of human genetic data.

57. Lastly, the Universal Declaration on Bioethics and Human Rights (2005) was met with mixed reviews.⁹ It seeks to provide a universal framework of principles and procedures in the field of bioethics.¹⁰ It addresses ethical issues related to medicine, life sciences and

⁴ Article 10.

⁵ Article 26.

⁶ Explanatory report, para.159.

⁷ Article 7.

⁸ Article 9.

⁹ Adele Langlois, "The UNESCO Universal Declaration on Bioethics and Human Rights: perspectives from Kenya and South Africa", *Health Care Analysis*, vol. 16, No. 1 (March 2008).

¹⁰ There has been some controversy in defining bioethics, so its exact definition was left out in the final version of the Declaration. Broadly it can be viewed as "regulation of biomedical research".

associated technologies as applied to human beings and stresses the importance of freedom of scientific research and the benefits derived from scientific and technological development. The consent requirements, articulated in article 6 govern any preventative, diagnostic, therapeutic intervention and scientific research, unless there is a legal basis, according to ethical and legal standards adopted by States and compatible with international human rights law. Consent, in general, ought to be prior, free, express and informed. The information on which to base the consent should be adequate and provided in comprehensible form, including possibilities for a withdrawal.

58. The domestic practice of forensic science is tailored according to the needs for evidence presentation in court. The protection of the public from criminal activities, which is a primary obligation of government, is balanced by the protection of fundamental ethical values and the respect for civil liberties in society, provided for by a national constitution or relevant legislation. In that light, values such as liberty, autonomy, privacy, informed consent and equality, while deserving of protection, are however not absolute and can be curtailed in the general interest of the public or to protect the rights of others.¹¹

59. In a practical sense, every person has an interest in privacy into which neither the State nor other persons should intrude without permission. Human dignity requires that a person has the right to control access to his or her own body and that any intervention is justified by both free, express and informed consent, or by law in consonance with human rights principles. It follows thus that any collection, use and circulation of personal information (such as biological samples and DNA profile), that is reasonably regarded as intimate or sensitive, needs to be controlled.

60. A particularly important issue with regard to forensic genetic identification has to do with the use of surviving family reference DNA profiles to identify victims. In such cases, the identification process is based on expected patterns of genetic relatedness among stated relatives. If the actual biological relationships among individuals in an identification case are not as they are represented or believed, there is a distinct possibility that this will be discovered in the course of the identification work. In such cases, the issues of consent and protection can be seen to extend beyond single individuals to impact their relatives as well.¹² The potential for harm suggests that this information should not be divulged to families. However, this must be balanced against the detriment that failure to investigate apparent discrepancies can have on the ability to provide identification (for example, apparent discrepancies may be due to simple misrecording or miscommunication of relationships). Further, not divulging apparent discrepancies may require restricting the access of individuals to their own data, and to information on the true status of their case. Failure to identify for unexplained reasons may itself alert the family that a discrepancy has been discovered, particularly if informed consent has properly informed the families of the risk, and the steps that will be taken not to divulge.

61. In many (however not all) instances, the risks associated with genetic data processing for forensic purposes can be minimized through appropriately tailored data collection and retention policies. Most notably, the risks related to family relationship discrepancies pose a peculiar challenge in this situation and therefore should be addressed

¹¹ See also Nuffield Council on Bioethics, *The Forensic Use of Bio-information: Ethical Issues* (London, Nuffield Council on Bioethics, 2007), paras. 3.33, 3.34.

¹² This is not conceptually unique to forensic identification, as in medical genetic diagnostic work hereditary conditions are often studied, with the results of a test possibly impacting individuals who themselves were not tested, and did not provide consent. Also, familial searching of criminal databases raises the prospect of genetic surveillance of individuals whose profiles have not been entered into the database under existing law, but those of their relatives have.

separately. European Union Directive 95/46/EC on the protection of individuals with regard to the processing of personal data and on the free movement of such data, although currently under review, is illuminating in that regard: personal data must be adequate, relevant and not excessive in relation to the purposes for which they are collected and/or further processed, and kept in a form which permits identification of the data subjects for no longer than is necessary for the purposes for which the data were collected or for which they are further processed.¹³

62. It seems clear enough as a standard that the retention period should not exceed the purpose for which personal data and biological samples were collected. However, there are instances in which retention periods can be long or possibly even indefinite. In particular, in the context of war crimes, crimes against humanity and genocide it may be necessary to preserve forensic evidence for a long time and in a manner that protects its integrity.

IV. Conclusions

63. **This report demonstrates that the use of forensic experts, and in particular the use of forensic genetics and the voluntary creation of genetic databanks, have a crucial role to play in identifying victims of serious violations of human rights and international humanitarian law. The report reveals the need to: (a) raise awareness of forensic genetics as enabling governments to comply with human rights obligations, in particular but not exclusively in the missing persons context, and (b) to refer to the requirement that such efforts be based on objective scientific methods to the maximum extent possible and ensure respect for human dignity and the protection of human rights and fundamental freedoms in the collection, processing, use and storage of human genetic data.**

64. **In that light, Human Rights Council resolution 10/26 on forensic genetics and human rights constitutes a necessary first step to providing guidance on a highly important and sensitive matter, as it directly refers the issue back to human rights as the ultimately decisive body of law.**

¹³ Article 6.