

This briefing summarises the implications for human rights of proposals to include the collection of DNA, and the storage of genetic information, in biometric identification schemes.

The nature of DNA and genetic information

- 1. DNA contains genetic information in the form of a string of chemical letters. The full sequence of these letters (the 'genome') is believed to be unique to an individual (unless they have an identical twin). Genetic information can be used to diagnose genetic diseases, predict some other health conditions, identify relatives (including paternity and non-paternity) and make inferences regarding the ancestry of the individual. Genetic information is therefore regarded as sensitive personal information.
- 2. Proposals to collect DNA for biometric identification (ID) databases may or may not specify legal restrictions on what genetic information is to be collected, stored and used. For criminal DNA databases, which have been established in a number of countries, whole genomes are not normally used and a legal restriction is normally put in place to restrict genetic information to specific parts of the genome referred to as 'non-coding' DNA. A forensic DNA profile is obtained and stored, based on only parts of the DNA, which do not reveal personal characteristics. This limits the interference with an individual's right to privacy by preventing personal information regarding health and other physical characteristics from being stored. However, even this more limited information remains sensitive. Such forensic DNA profiles act as a 'genetic fingerprint' or biometric, enabling individuals to be identified through matching their stored DNA profile with a DNA profile from a crime scene, for example. However, unlike other biometrics, a forensic DNA profile can also be used to identify relatives (including paternity and non-paternity) and make inferences regarding the ethnicity or ancestry of the individual. Therefore, forensic DNA profiles are also regarded as sensitive personal information.
- 3. To obtain DNA, it is extracted from a sample of a person's cells (contained in blood, hair roots, saliva etc.) and this is analyzed in a laboratory to obtain the required genetic information, which can be stored as a string of numbers on a computer database. Collection of DNA without consent is regarded as a violation of a person's bodily integrity. Whilst a number of countries do collect DNA without consent from a limited number of citizens, this occurs only in circumstances proscribed by law, where such violations are regarded as necessary and proportionate to the need to investigate criminal or terrorist offences. This requires the adoption of extensive legal safeguards and tight restrictions on whose DNA may be collected in this way.

Dangers and misuses of stored DNA and genetic information

- 4. A person's DNA is left wherever they go, for example on a coffee cup. This means a DNA database allows the government, police, or anyone who gains access to it, to track individuals and their families, even if they have not committed crimes. This can be done by matching a DNA profile, found for example on a coffee cup at a political meeting, with a stored DNA profile in the computer database, which then provides details about the individual's name and address etc. If the whole population is on a DNA database, it is open to abuse by governments or anyone who can infiltrate the system: for example by criminals wanting to track down victims, including high profile figures such as politicians or members of the security services, whose safety may be dependent on not revealing their identities.
- 5. Unlike fingerprints, DNA profiles can be used to identify an individual's relatives. Because an individual inherits half their DNA from their father and half from their mother, a DNA database of a whole population can be used to find a person's parents, children, siblings and more distant relatives by comparing their DNA. This process of searching a DNA database to find relatives is known as "familial searching". If a person's father or child is not really biologically related to them, "nonpaternity" can be discovered easily by comparing the DNA profiles of the father and their supposed children. The discovery of non-paternity can obviously have very serious impacts on families. In most countries, relatedness and non-paternity is regarded as a private matter that may be investigated within the family but should not be exposed by others, including by the police or government. Building a universal DNA database risks the break-up of families by making it easy to discover nonpaternity. For example, the database could be misused by a corrupt official or anyone who can infiltrate the system and gain access to the data. If criminals gain access to information about non-paternity they might blackmail an individual or their family by threatening to reveal this information.
- 6. Individuals' genetic information may also be analysed to identify more distant relatives or infer genetic ancestry or lineages. This raises additional concerns that a DNA database may be used to facilitate identification of, and potential discrimination against, persons of different ancestries. The likelihood of errors increases the larger a DNA database is, because more samples are being analysed and more computer searches are being conducted. The most frequent source of errors is mix-ups or contamination of samples, either at the laboratory or before the samples get there.¹ Errors are also more likely to occur where DNA from a crime scene contains a mixture of cells from more than one person (which is often the case in rape cases).^{2,3,4} A person's DNA can also be transferred to a murder victim or a weapon, even if they never touched it, falsely implicating them in a crime.⁵
- 7. False matches occur because (i) a forensic DNA profile is not unique (it is based only on parts of the DNA); (ii) there are many sources of human error in the process of analysis, e.g. samples can be mixed up or degraded.
- 8. DNA identification is not foolproof. People who have been affected by mix ups of DNA samples include a teenager in England who spent three months behind bars for rape in city he had never even visited⁶; and an 18 year old in Las Vegas who spent 4 years in gaol for a robbery committed by his cousin⁷. In Houston, Texas, DNA samples were tampered with or contaminated and one result was that teenager Josiah Sutton was convicted and sentenced to 25 years in prison for a rape he did not commit.⁸ In New York, a student protestor was wrongly linked to a killing by DNA

collected while she was protesting.⁹ In England, Peter Hamkin was held by police for 20 days for an alleged murder in Italy, before it was discovered that a mistake with the DNA evidence had been made by Interpol.¹⁰

No country in the world has legislation which allows the inclusion of DNA as part of a national ID system

- 9. Mandatory collection of DNA from whole populations violates international principles on human rights.
- 10. Two countries (Kuwait and Kenya) previously passed such laws but these have both since been annulled on human rights grounds.

In Kuwait, the DNA law, Law No. 78 of 2015, required all Kuwaiti citizens, foreign residents, and temporary visitors to submit DNA samples to a database to be maintained and operated by the Interior Ministry.

In October 2016, following internal and international criticism and an appeal from the Emir of Kuwait, the parliament of Kuwait agreed to revise the law to restrict the collection of DNA to those suspected of committing criminal offences. On 5th October 2017, the Constitutional Court found that the DNA law violated articles 30 and 31 of Kuwait's constitution, as well as Article 17 of the International Covenant on Civil and Political rights, to which Kuwait is a party.¹¹ The ruling is final.

In August 2016, before Kuwait's DNA law was annulled, the Human Rights Committee considering the third periodic report of Kuwait under the International Covenant on Civil and Political Rights found that it imposed unnecessary and disproportionate restrictions on the right to privacy.¹² The Committee was particularly concerned about the compulsory nature and the sweeping scope of DNA testing; the broad powers of the authorities and the Ministry of the Interior to collect and use DNA samples; the lack of clarity on whether necessary safeguards are in place to guarantee the confidentiality and prevent the arbitrary use of the DNA samples collected; the absence of independent control and the inability to challenge the law before an independent court. It recommended that Kuwait amend the law to comply with its obligations under the Covenant, with a view to (a) limiting DNA collection to individuals suspected of having committed serious crimes and on the basis of a court decision: (b) ensuring that individuals can challenge in court the lawfulness of a request for the collection of DNA samples; (c) setting a time limit after which DNA samples are removed from the database; and (d) establishing an oversight mechanism to monitor the collection and use of DNA samples, prevent abuses and ensure that individuals have access to effective remedies.

In 2018, Kenya adopted legislation allowing the government to collect DNA from every citizen as part of its national identity scheme, under the Statute Law (Miscellaneous Amendments) Act 2018. The judgment of Kenya's High Court, in January 2020, was that the collection of DNA for purposes of identification "*is intrusive and unnecessary, and to the extent that it is not authorised and specifically anchored in empowering legislation, it is unconstitutional and a violation of Article 31 of the Constitution*". This aspect of the legislation was therefore ruled to be null and void.¹³ Other aspects of the national ID scheme were put on hold until an appropriate and comprehensive regulatory framework is put in place.¹⁴

11. In the UK, innocent people's DNA profiles have been removed from a DNA database, and stored DNA samples have been destroyed following a judgement by the European Court of Human Rights. The Grand Chamber of the European Court of Human Rights delivered a unanimous judgment in 2008, in the case of S. and Marper v. the UK, deciding the indefinite retention of biological samples, forensic DNA profiles, and fingerprints in England and Wales at that time was a breach of Article 8 of the European Convention on Human Rights.¹⁵ The judgment states: "*In conclusion, the Court finds that the blanket and indiscriminate nature of the powers of retention of the fingerprints, cellular samples and DNA profiles of persons suspected but not convicted of offences, as applied in the case of the present applicants, fails to strike a fair balance between the competing public and private interests and that the respondent State has overstepped any acceptable margin of appreciation in this regard. Accordingly, the retention at issue constitutes a disproportionate interference with the applicants' right to respect for private life and cannot be regarded as necessary in a democratic society."*

The UK Government has since taken steps to rectify the situation, adopting an Act which mandates the removal of innocent people's DNA profiles from the computer database, and which requires the destruction of DNA samples within six months of collection by the police.¹⁶ The Protection of Freedoms Act 2012 led to the removal of over 1.7 million DNA profiles taken from innocent people and from children from the DNA database and the destruction of 7,753,000 biological samples.¹⁷ Figures collected by the Government had shown that keeping innocent people's records on the DNA database did not help to solve more crimes and retaining samples raised privacy concerns whilst not being useful for identification purposes.¹⁸ Following the significant reduction in the size of the DNA database the UK Home Office reported that "*The reduction in profiles held from innocent people has not led to any reduction in the number of matches the database produces*" and stated "*We have transformed it from a database that infringed the privacy of innocent citizens to one that is proportionate and still effective*".¹⁹

Since the judgement, many other countries have adopted new DNA database laws which are compliant with this judgment.

12. A number of countries have established national genetic databases (biobanks) for undertaking health research, but people provide their DNA to these biobanks only <u>with consent</u>.

For example, in Estonia, there is a population-based biobank, which links DNA samples to medical records.²⁰ However, it does not contain DNA samples from the whole population: currently there are samples from 51,535 volunteers (about 4% of the population), all of whom have signed a form giving their consent to the use of their genetic data for medical research. Fully informed consent to medical research is a requirement of the World Medical Association's Declaration of Helsinki.²¹ In addition, the Estonian Biobank is regulated under the Human Genes Research Act²². The consent form used in Estonia states that "No one may force me to become a gene donor" and states that the identity of the gene donor must remain unknown to anyone who receives data from the biobank.²³ Other safeguards include a right to apply for the data to be destroyed and to claim compensation for damage. This is completely different to proposals to include DNA in biometric ID schemes, which envisage that collection of DNA from the whole population is made compulsory for everyone and used as a means to reveal and verify identity. In the light of the judgement in the Marper case, highlighted above, retention of DNA samples and genetic data from the general population without consent would in any case not be lawful in Estonia, as this would be in breach of Article 8 of the European Convention of Human Rights.

13. In the past, a few other countries have proposed building a universal DNA database for their whole population but none of the proposals have ever been implemented.

For example, the Portuguese government announced in 2005 that it wished to put its entire population on a DNA database.²⁴ However, this plan was abandoned due to concerns about costs and human rights and Portugal adopted much more restrictive DNA database legislation in February 2008.²⁵ Uzbekistan also back-tracked from proposals to put its entire population on a DNA database and has instead proposed a focus on convicted persons serving sentences for serious crimes.^{26,27} In 2009, the United Arab Emirates (UAE) announced it would include its entire population on a DNA Database.²⁸ However, this proposal was widely criticised and has not been implemented in practice. In response to the proposal, Professor Sir Alec Jeffreys, the British geneticist discovered the forensic use of DNA, was quoted as saying there needed to be "full transparent justification of why a universal database is needed compared with a criminal DNA database" and "I would need very substantial reassurance on the type of information that will be stored in that database, on the security of that database".²⁹

Universal DNA databases provide no benefit in tackling terrorism or solving crime and incur substantial costs

- 14. Storing individuals' DNA profiles on a database only helps to solve a crime if that person goes on to commit a crime or terrorist act for which DNA evidence is relevant. Because most people are not criminals or terrorists a universal database diverts resources away from likely suspects by spending substantial resources on collecting and storing DNA from individuals who are very unlikely to commit crimes.
- 15. The lack of value is best illustrated by the UK example described above, where removing more than 1.7 million people's records from the police DNA database did not reduce the role of DNA in solving crimes at all. This is because these individuals removed from the database were either completely innocent, or were children convicted of minor offences who did not go on to commit more crimes.
- 16. In the USA, the cost of analysing one individual's sample to obtain a DNA profile has been estimated at \$40³⁰ making the total cost of analysis significant for any country's whole population (assuming that forensic DNA profiles are stored, rather than more comprehensive genetic information, which would be considerably more expensive). Infrastructure funding will also be required: for example, the UK Home Office spent £1.22 million in 2016-17 running the UK DNA Database.³¹ As noted above, this UK database is not a universal database: it contains DNA profiles from 5.25 million people, less than 8% of the population, and persons not convicted of criminal offences are continually removed from it. The costs of establishing a new universal database would also include setting up the infrastructure and collecting samples of saliva (usually using mouth swabs) from the whole population. The costs of sample collection are difficult to estimate and could rise substantially if large numbers of people refuse to give their samples, which would necessitate the use of force.

International requirements for safeguards for the collection, storage and use of DNA

17. To meet international privacy standards enshrined in the International Covenant on Civil and Political Rights, a DNA collection and retention mechanism must be extensively regulated, narrow in scope, and proportionate to meeting a legitimate security goal. In addition, international best practice would require any government which collects DNA to incorporate further safeguards into its DNA gathering system, including legal provisions to restrict the circumstances in which DNA may be collected and retained and restrictions on the purposes for which stored data may be used.

18. International best practice has been outlined in the report 'Establishing Best Practice for Forensic DNA Databases', available on: <u>http://dnapolicyinitiative.org/report/</u>. This report includes an extensive list of requirements for safeguards, with examples from the national legislation of multiple countries worldwide, for example: for fully informed consent, quality assurance of laboratories, restriction of purposes, rules for expungement of data and destruction of samples, etc. These safeguards should be enshrined in law before establishing a DNA database.

Use of DNA for the identification of deceased persons

19. It is sometimes claimed that a universal DNA database will assist in identifying deceased persons. Whilst it is correct to state that DNA can be used for this purpose. it is important to also consider practicalities, ethical issues and regulations required for such a purpose. Establishing a national DNA database of every individual is neither necessary nor proportionate to such an aim: such a DNA database does not exist in any country where DNA has been used for identification of deceased or missing persons. Normally, the DNA match needed to identify a victim of a mass disaster is made with a source of DNA known to come from the individual (such as their toothbrush), or by using partial matches with the DNA of close relatives. The DNA of relatives is collected only with their fully informed consent. In addition, numerous legal safeguards are needed, such as quality assurance for laboratories and measures to protect privacy. Further, identification of decomposed bodies requires specialist techniques which means that standard forensic DNA profiles, such as are normally stored in a criminal DNA database, are often inadequate, and more detailed, non-standard methods need to be used. It would be unrealistic and extremely costly to include such detailed genetic profiles in a national ID database.

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