

Chapter 6

Familial searching,
inferring ethnicity
and research uses



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Introduction

- 6.1 In this chapter we consider the expansion of uses of the National DNA Database (NDNAD). When the Database was first established, it was limited in its use to the matching of DNA profiles with crime scene samples. As the Database grew, speculative searching could be undertaken. With the massive growth of the Database, the uses to which the DNA profiles, and indeed the retained biological samples, can be put have expanded.
- 6.2 The Police and Criminal Evidence Act 1984 makes clear that police bioinformation databases may only be used for:
- the prevention or detection of crime;
 - the investigation of an offence;
 - the conduct of a prosecution; or
 - identifying a deceased person or a body part.

It precludes their use in medical or other research, or in paternity disputes.¹ Such terms, however, may be subject to a wide interpretation that expands the range of uses to which the information on the databases may legitimately be put. While, to date, forensic databases have been used primarily to 'match' known suspects with crime scenes, they are increasingly used in efforts to identify unknown suspects: by searching the NDNAD for possible relatives of a perpetrator, or for predicting the likely ethnic appearance of an unidentified suspect, for example.

- 6.3 While most of the uses of the NDNAD can be classified as 'operational', in that the use is directly related to particular police investigations, there are now emerging 'research' uses of the Database. Research could be conducted using the electronic records ('profiles') on the Database or the archived biological samples from which the DNA profiles have been generated. In considering research uses it is therefore important to distinguish between these. The House of Commons Science and Technology Committee has noted that biological samples have already been used for research and has recommended that independent studies be undertaken on public attitudes to this.²
- 6.4 Expanding use of the NDNAD beyond operational uses makes crucial the need to introduce robust forms of ethical oversight and management of these uses, particularly in instances where the research uses the archived biological samples. These samples contain sensitive personal genetic information and their use warrants stricter regulatory oversight. Advanced levels of ethical and scientific review are necessary as these samples are not initially obtained with consent, unlike those collected in medical settings, and remain easily traceable to named individuals. This chapter first considers 'operational' uses of the NDNAD before turning attention to broader 'research' uses of the Database and stored biological samples.

1. *Lambeth London Borough Council (Applicant) v (1) S (2) C (3) V (4) J (By his children's guardian N) (Respondents) and (1) Commissioner of Police of the Metropolis (2) Secretary of State for the Home Department (Intervenors) (2006)* [2006] EWHC 326 (Fam).

2. House of Commons Science and Technology Select Committee (2005) *Forensic Science on Trial*, paragraph 87.

Operational use of the NDNAD profiles and biological samples

Quality assurance

6.5 We note that the use of the NDNAD to improve operational performance and DNA analysis procedures, and to guarantee the quality of the Database itself, is non-contentious. Compulsory quality assurance procedures include re-analysing a proportion (usually five to ten per cent) of randomly selected biological samples to check laboratory error rates. This can provide statistics on the performance of the NDNAD that may be used to identify weaknesses. Whilst this may be an acceptable use of both data and samples, there is a lack of transparency about the exact nature of such projects, making it difficult to assess how, or if, this statistical research might be related to other research that has been concurrently undertaken (see Chapter 7 on transparency). The use of the NDNAD for 'quality assurance' is now classified as 'routine management information' and not deemed research.

Familial searching

6.6 When a crime scene profile does not match any stored profile, it is possible to undertake further testing to see if it partially matches any of those held on the NDNAD. Such a partial match might mean that the crime scene stain was left by a (genetic) relative of the person to whom the partial match is made. The Forensic Science Service (FSS) Forensic Intelligence Bureau first offered this 'familial searching' service to support the investigation of some serious crimes, and other forensic providers now also perform the service.³ Familial searches can only be conducted with the specific authority of the Custodian of the NDNAD (see Chapter 7). Home Office statistics state that 73 familial searches were undertaken in 2004, 78 in 2005⁴, and 115 in 2006.⁵ As explained in paragraph 2.16, the search is likely to produce very many possible partial matches. This severely limits the usefulness of familial searching. The size of the pool must be limited geographically and/or by other means to produce a useful shortlist for police, to be investigated using standard police methods.

6.7 The Association of Chief Police Officers (ACPO), the Home Office, the Information Commissioner, and representatives from the Human Genetics Commission have agreed upon the circumstances in which familial searches will be performed and the confidential results integrated into an investigation. However, the details of this agreement are described as 'operationally sensitive'. It is not a public document and has not been disclosed to our Working Group.

6.8 Many respondents to our consultation remain seriously concerned about whether familial searching is an unjustifiable intrusion into personal privacy, given its potential to reveal family secrets (see Box 6.1). There is a clear need to maintain strict protocols relating to the use of familial searching and the confidentiality of information derived from the process. However, the public have yet to be reassured that appropriate safeguards are in place. In the scenarios detailed in Box 6.1, the risks of revealing unknown biological relations, or the absence of relations where they are presumed, are relatively small. Although this is highly sensitive information, and 'Mr X' may not wish to find out from the police who his biological father is (assuming he did not already know), whether this is indeed revealed depends upon the degree of confidentiality with which the police treat this information. The public fear of revelation of family 'secrets' may therefore be more to do with the heightened sensitivity of the issues than the actual risk posed.

3. The Forensic Science Service has considered the utility of such extended database searches since 1996 after an internal paper on 'near-misses'. Some of this work arose from efforts to deal with 'close-relative defences'. (See for example Evett I (1992) Evaluating DNA profiles in a case where the defence is "it was my brother" *Journal of the Forensic Science Society* 32(1): 5–14).

4. Mr Sutcliffe, House of Commons, Hansard, 9 May 2006, column 209W.

5. Written Answer to Parliamentary Question from Norman Baker, 17 January 2007.

Box 6.1: Familial searching – scenarios

Suppose Mr X left his DNA at a crime scene. He may be the criminal or there may be an innocent explanation; either way the police want to identify him as part of their enquiries. They obtain a DNA profile from the crime scene and search the NDNAD. No match is found. They then use familial searching to see if any profile on the NDNAD might come from one of Mr X's relatives.

Note that a partial match would not prove that an identified person is Mr X's relative, or even make it highly probable. For example, paternity testing as done for family courts relies for its accuracy on having DNA from the mother as well as the alleged father.

In this hypothetical case the familial search brings up two possible hits, Mr A and Mr B. Mr A and Mr B are asked to provide names and addresses of any sons (for example). The names are given and each son is asked to provide a biological sample. Now we imagine two circumstances where there is a family secret:

Case 1: Mr X is in fact an illegitimate son of Mr A. If Mr A chooses to reveal this secret to the police, Mr X will be tested and any court case (if there is one) will rely on the match between Mr X's DNA and the crime scene profile. If Mr A does not reveal the secret, or maybe is unaware of it, Mr X will not be on the list of sons he provided to the police, so will not be tested. Even if Mr X is later identified through some independent line of enquiry, there would be no reason to link him to Mr A. The only way the relationship would become known to the police is by Mr A volunteering this information. The only way the paternal relationship would then be revealed to Mr X would be if the police were to reveal the secret. However, there is a possible risk that the police might reveal this information if Mr X sought the grounds upon which he was being asked for his DNA.

Case 2: Unknown to both, Mr B is not the biological father of his son Y. In that case Y's DNA profile will bear no relation to Mr B's profile, and hence no relation to Mr X's profile. Having been eliminated from the enquiry, Y is of no further interest. Laboratories do not report the actual marker alleles that make up the profile; the report will state that there is no match between Y's profile and that obtained from the crime scene. At no time will any report or analysis list the actual alleles of Y's and Mr B's profiles alongside one another, so that the incompatibility might be noticed.

Case 2, for example, suggests that the practice of profile comparison underlying familial searching might not always pose the substantial risk that may be presumed from initial consideration of the technique. The risk of directly making public information that particular family members either do not wish the police or others to know, or do not themselves already know, may be small if the police were to handle their inquiries and the information derived from them with the utmost diligence and integrity. Not only do the police need to be careful how they approach the persons whose profiles are on the NDNAD and their possible relatives, but also adhere stringently to the principle that any information about genetic relatedness (or its absence) remains entirely confidential to the relevant scientific and investigative teams.

- 6.9 Some respondents to the consultation were also concerned that familial searching may be carried out for 'non-forensic' uses, either by individuals who wish to capitalise on information about the existence of biological relations between individuals, and/or employees of agencies, institutions or organisations (such as the Family Court, social workers or the Child Support Agency) who may wish to establish paternity or other familial relations. It should be reiterated that it has been affirmed that it would be illegal for the Family Court to compel police to reveal information from forensic biological samples to assist with paternity inquiries as this was not a purpose described in the Police and Criminal Evidence Act 1984.
- 6.10 The legal parameters for use of the NDNAD are clearly delineated: the prevention and detection of crime, the investigation of an offence, the conduct of a prosecution – or the identification of a deceased person. This affords some certainty about how the NDNAD may be lawfully used, in that it is clear that it cannot be used in paternity, or other disputes. However, in light of public concerns about the use of familial searching, further information on how it is being used operationally and clear accountability are required. It is also imperative that whatever guidelines do exist be compared with actual practice, particularly because it is recognised that the consequences of any resulting police inquiries may resonate widely within the family and the community for some time after initial inquiries are made, especially after media attention or when a criminal case proceeds to court.
- 6.11 The aim of familial searching may be to provide legitimately useful intelligence in crime solving and there may be instances in which its use is able to be justified and is proportionate (for example, tracing the male relatives of an unidentified serial killer may be deemed a justifiable intrusion into familial relations). However, before the technique is implemented on a wide scale, public fears should be recognised by introducing clear and explicit guidelines on its use and these should be made available for scrutiny. In light of the potential for familial searching to

reveal previously unknown or concealed genetic relationships, and for publicly revealing a relationship with an offender, there must be adequate safeguards to protect against any possible unwarranted intrusion into family privacy. **While we do not believe that familial searching interferes with privacy rights to an extent that should prohibit its use (see paragraphs 3.3–3.7), it is our view that the potential benefits for crime detection must be balanced carefully with any potential for harm. The lack of consent obtained when sampling makes the use of the NDNAD in searching for relatives particularly sensitive. It is important therefore that this technique is not used unless it is necessary and proportionate in a particular case. Before it is more widely deployed, there needs to be detailed and independent research on its operational usefulness and on the practical consequences for those affected by it.**

Inferring ethnicity

6.12 The inferring of ethnicity is a statistical process that can be applied to a particular DNA profile, with the aim of predicting the ‘ethnic appearance’ of the unidentified individual to whom the DNA profile relates (see paragraph 2.17 and Box 6.2). The NDNAD (unlike the Scottish DNA Database) contains information on an individual’s ‘ethnic appearance’. This is based on visual judgments made by police officers about those from whom they are taking a biological sample, or on that person’s invited self-classification. Police officers routinely classify suspects into one of seven categories for recording, statistical and other purposes throughout the criminal process. These ‘ethnic appearance’ categories, as recorded on the PNC are:

- Afro-Caribbean
- Arab
- Asian
- Dark Skinned European
- Oriental
- White Skinned European
- Other.

6.13 These generalised and subjective categories may help police officers communicate with each other, but they do not correspond with the types of classification used in population genetics research. A police officer’s perceived assignment may also not accord with a self-assignment. As Cho and Sankar⁶ have illustrated, the use of such labels varies greatly over space and time, and in some groups they are rarely applied, even by the individuals themselves, with any consistency. In biological terms, human beings are one undifferentiated species. Visible differentiations in skin colour or other characteristics are the product of complex interrelationships between genetic factors, as well as environmental and social factors that are highly variable: for example skin colour may be influenced by extent of exposure to sunlight. Thus apparent ethnicity may not be well predicted by reference to a relatively small set of short tandem repeat (STR) loci.

6.14 The FSS and other forensic suppliers offer to make inferences about an offender’s likely ethnicity from crime scene DNA profiles, such inferences being based upon calculations arising from research previously undertaken on a sample of NDNAD profiles. Results for an individual will, however, in general be limited because the chain of inference between DNA profile and ethnic appearance is long, and every link is loose:

- The different alleles of markers in the SGM+ profile appear with different frequencies in different ethnic groups, but the frequencies are statistical properties of groups, not individuals. All alleles can be found in all groups.

6. Cho M and Sankar P (2004) Forensic genetics and ethical, legal and social implications beyond the clinic *Nature Genetics* 36: 58–12.

- Ethnicity can rarely be accurately summed up by a single label or category.
- The seven ethnic appearance categories are not straightforwardly related to actual ethnic origin.
- Ethnicity is often only loosely linked to actual appearance.

6.15 Our public consultation revealed considerable concern about the use of DNA profiles to make ethnic inferences, and about research into this area (Box 6.2). This centred upon the flawed assumption that it is possible to assign accurately and consistently a 'racial type' both to individuals and to the population groups against which their identity can be compared. Behind the concerns may lie an anxiety that the classification of people into seven 'ethnic appearances' may seem closer to racist ideas than to genetic understanding of ethnicity, and that the research is seen by some people as attempting to lay a scientific foundation for racial categorisation. Much mainstream genetic research is indeed devoted to exploring the differences between human populations and making inferences about ancestry. However, the results of genetic research do not support the idea that humans can be classified by appearance into a limited number of 'races'.

Box 6.2: Ethnicity research using forensic DNA

Information on the perceived ethnicity of offenders has been used to undertake several research projects using DNA collected for forensic use in recent years. At least five requests have been made to access either stored biological samples or DNA profiles (we do not know which) with the intention of analysing them for research into markers of ethnicity. Since 2003 three such requests have been approved. No evidence is available for requests of this nature made before 2001. In 2004 it was reported that the police were requesting ethnic inferences after two Forensic Science Service (FSS) scientists had published research on the use of DNA profiles for inferring the ethnic origin of the donor of a crime scene stain based on studies undertaken on data and profiles stored on the NDNAD. Other projects have been undertaken by scientists at the FSS that seek to predict ethnicity on the basis of frequencies of Y-chromosome haplotypes (combinations of marker alleles that are inherited largely unchanged through the male line). These have been widely used in anthropological research to give information on male ancestry. Research into regional genetic variations has also been undertaken by the FSS. This has extended analysis to a consideration of the existence of genetic variations between particular ethnic groups located in specific regions. It is not known whether this research used DNA profiles or the original biological samples.

- 6.16 Ethnicity tests provide only an inference for use during a police investigation and are not used as evidence supportive of the prosecution if the suspected offender is found.⁷ The information can be used to help reduce a 'suspect pool' and inform police priorities, and may support or contradict any witness statements reporting that the offender had a specified ethnic appearance. Although an ethnic inference may have no prosecutorial power, significant ethical and practical concerns remain. Making an ethnic inference may lead police to narrow the focus of their enquiries prematurely in expectation that the offender will come from a particular racial or ethnic group (referred to as 'tunnel vision').⁸ Such tunnel vision has been implicated in subsequent miscarriages of justice. It may also reinforce existing prejudices about the likely perpetrators of crime and support generalisations about the supposed 'predisposition to crime' of populations based upon conclusions of research conducted on small and arguably 'skewed' samples.
- 6.17 **In view of the significant ethical and practical problems, and the limited usefulness of the information provided, attempts to infer ethnicity from DNA profiles and samples fail the test of proportionality and we recommend that ethnic inferences should not be routinely sought, and should be used with great caution.**

7. National DNA Database (2006) *The National DNA Database Annual Report 2004–2005*, p35.

8. See McCartney C (2005) The DNA Expansion Programme and criminal detection *British Journal of Criminology*, for the risks of 'tunnel vision' in police investigations using DNA; and Duster T (2006) Explaining differential trust of DNA forensic technology: grounded assessment or inexplicable paranoia? *Journal of Law, Medicine & Ethics* 34(2): 293–300 for an assessment of the racial implications of the use of DNA 'dragnets' in the USA.

6.18 Some further research in this area may be legitimate and ethically neutral. It may be unobjectionable to use anonymised profiles from the NDNAD to explore whether a predictor of the reported ethnic appearance could be developed. On the other hand, as we discuss further in paragraphs 6.41–6.43, it would be improper for researchers to use NDNAD data to investigate supposed racial propensities to crime.

Non-operational research use of the NDNAD and biological samples

Non-operational research and function creep

6.19 ‘Function’ or ‘mission’ creep occurs when a project or mission is expanded beyond its original goals. In the case of forensic bioinformation databases this could be evidenced by the expansion of databases to include constituencies that were not originally intended as targets, and by extending the uses to which the databases can be put. For example, DNA profiling was originally introduced to help identify criminals who left retrievable biological material such as blood, semen, saliva and hair at crime scenes (or on victims or witnesses). These were, typically, violent criminals and sex offenders. Forensic bioinformation databases have now been extended to include not only individuals convicted of relatively minor offences but also arrestees, volunteers and others who are innocent of involvement in crime. These developments raise concerns that we are witnessing ‘function creep’, concerns articulated by Sir Alec Jeffreys, who pioneered DNA fingerprinting:

“The real concern I have ... is with what I see as a sort of mission creep. When the database was initially established it was to database DNA from criminals so that if they re-offended they could be picked up. There are now hundreds of thousands of entirely innocent people now populating that database, people who have come to the police’s attention as a result of being charged with a crime but subsequently released. My view is that that is discriminatory.”⁹

6.20 Although less attention has been drawn to the use of the NDNAD for non-operational research, the issues it raises are disquieting. Research on DNA profiles and archived biological samples has extended the uses to which the NDNAD is put. The attractiveness of the NDNAD as a source of data for researchers, such as behavioural geneticists, is likely to make it the subject of further research interest. The imperative to find new ways of reducing offending offers a compelling rationale for governments to allow such research. As has been noted, “the history of fingerprinting [has] demonstrated that criminal identification databases are powerful resources subject to political manoeuvres that can quickly push them beyond their original mandates – the well-established and growing interest in behavioural genetics may contribute to these manoeuvres”.¹⁰ The need to ensure that all research uses of the NDNAD are subject to rigorous ethical review and independent monitoring cannot be overstated.

6.21 Research using the NDNAD should be specifically for the purposes of criminal investigation and detection – i.e. for operational reasons – and non-operational research use could constitute a very broad, and some could argue inappropriately wide, interpretation of that remit. The present criteria for using the bioinformation stored are the “prevention or detection of crime, the investigation of an offence, or the conduct of a prosecution”, criteria that can be construed widely. **We make a general recommendation that all research proposals using the NDNAD and stored samples should be formally, independently and transparently evaluated.**

9. BBC Radio 4, *Today* programme, 1 November 2006.

10. Sankar P (2001) DNA-Typing: Galton’s Eugenic Dream Realized?, in *Documenting Individual Identity* Caplan J and Torpey J (Editors) (Princeton University Press), pp273–90, pp286–7.

Openness and public scrutiny

- 6.22 Potential research on DNA profiles or samples is limited by the Police and Criminal Evidence Act (PACE) 1984 to that which is related to the prevention and detection of crime. In deciding upon granting permission for research using data on the NDNAD, the Strategy Board considers whether there is a police need for the purpose for which access is requested, and the legality and ethical aspects of the purpose. In March 2004, Home Office Minister Hazel Blears reported that only five requests to undertake research projects on the NDNAD had been received, of which two had been approved by the NDNAD Strategy Board, two rejected and one was yet to be decided.¹¹ These requests were decided in the absence of the kind of detailed information about the nature of the projects that would now routinely accompany similar requests to other like biobanks in the United Kingdom (see Chapter 7).
- 6.23 Since this reporting of research requests, the number has rapidly increased. A list of research proposals put to the NDNAD Strategy Board prior to December 2006, indicates that 33 requests had been made to conduct research, of which 19 were approved and 14 refused. The information provided in the table released by the NDNAD Strategy Board is cursory, however.¹² There are instances in which the principal investigator remains unidentified or where the status of the research is unknown. In all cases only the most perfunctory description of the research is offered (usually just a title) and it is not possible to establish with any certainty the purpose of the research. It is also difficult to determine whether requests are being made to meet police operational needs or as part of a wider research agenda.
- 6.24 The table provided by the NDNAD Strategy Board shows that six requests have been approved (two operational and four research-based) to obtain *identifying* information about individual profiles on the NDNAD. Several others were disallowed. It is not clear what information was sought (whether relating to individuals or groups) or for what purpose. The first of the two approved operational requests was made by police to check for 'named individuals', but it is not clear what this might mean. Further clarification was provided which explained that such requests related to "seeking named suspects in a specific inquiry at the police's request". This is still far from explaining such a use of the NDNAD. If the police seek a DNA match on the NDNAD and one is found, then that individual's name will be readily known by the police. If the police sought a named individual's DNA profile for purposes other than making a match to one found at a crime scene, this might signal a departure from the purposes for which the NDNAD may be lawfully used. It remains far from clear what the results were of these research requests.
- 6.25 **At present, there is a significant lack of transparency concerning research using the NDNAD and stored samples, with the cursory details provided in the NDNAD Annual Report being inadequate. Given this lack of information, it is not possible for the public to be reassured that research projects will only be approved if their potential benefits are sufficient to outweigh the harm to the other interests involved. We recommend the regular publication of further details concerning, as a minimum:**
- information on requests and approvals, including the criteria used to determine approval or refusal;
 - whether there was informed consent for the use of biological samples;
 - which individuals have been given approval to undertake research projects using the NDNAD and stored samples;
 - exactly what the purpose of this research was;

11. Hazel Blears MP, House of Commons, Hansard, 17 March 2004, column 345W.

12. National DNA Database (2007) *The National DNA Database Annual Report 2005–2006*, p43.

- whether the research has been subject to adequate levels of scientific and ethical review; and
- the outcomes of research.

Regulation of research using forensic bioinformation

6.26 Since the passage into law of the Human Tissue Act in 2004, it has become a requirement that researchers who approach 'biobanks' or large DNA databases with requests to access their stored informational or biological resources for medical, epidemiological, sociological or other research purposes have their proposals subject to detailed ethical and scientific review, with documentation placed either in the public domain or made available under a Freedom of Information request. This documentation typically involves submitting to the custodian of the bank a very detailed set of documentation clearly outlining:

- which samples, data or information they wish to access;
- an explicit and detailed description of the proposed research project;
- the methodologies they intend to employ;
- an assessment of the ethical implications of the research;
- a summation of the staff who will be working on the project;
- the intended outcome of the project including the likely dissemination of published findings and arrangements for public deposition of findings or materials (such as datasets) created from the project which must be updated and reported at the conclusion of the project; and
- a Material Transfer Agreement¹³ that legally regulates the parties that may access the required resources and the terms and conditions under which they may do so.

6.27 Forensic providers have explained that up until very recently, access requests took the form of an 'exchange of letters' between the company and the NDNAD Custodian. During 2006 a standardised form was produced which has recently become available for scrutiny. However, it still appears not to offer the level of detail that would ordinarily be required for medical research purposes. Thus, the decision-making body that approves requests for research access, the NDNAD Strategy Board (see paragraphs 7.30–7.32 for details), may have inadequate information to make informed decisions about the scientific worth, ethical robustness, or utility for the police of the research proposals before it.

6.28 Criticism of the lack of proper ethical oversight of research requests prompted a commitment by the Home Office to establish a dedicated Ethics Group in the summer of 2007 (see paragraph 7.19). Such a committee is vital because it cannot otherwise be guaranteed that research is not ill-conceived or poses risks to individuals through inadequate anonymisation, or acts to perpetuate racial or other stereotypes. The new Ethics Group will not be able to discharge its task unless adequate information or documentation is produced on proposed research. This is a priority. It also appears from the documentation that it will be determined by the NDNAD Strategy Board whether or not the Ethics Group will be asked to consider a research proposal – referral to the Group does not appear to be automatic. The Strategy Board could therefore decide not to refer a research proposal to the Ethics Group, or of course could ignore its advice if it so chose. Such decisions and their reasoning should be made publicly available (see Chapter 7).

6.29 At present, The Human Tissue Act (2004) S. 39(1), excludes any activities undertaken 'for criminal

13.A Material Transfer Agreement (MTA) is a contract that governs the transfer of tangible research materials between two organisations, when the recipient intends to use it for his or her own research purposes. The MTA defines the rights of the provider and the recipient with respect to the materials and any derivatives.

justice purposes' from the general remit of the Act. Researchers who wish to access the NDNAD resources are not, therefore, necessarily required to provide the same level of information about their prospective research projects as is demanded of researchers who wish to access other similar tissue banks and bioinformation databases in the United Kingdom.

- 6.30 It is not clear that a compelling argument can be sustained to support such a broad exception. The practicalities of police work are such that it would be entirely inappropriate to require forces to submit operational requests to detailed ethical and scientific review. It is not evident, however, that non-operational research projects – particularly those that involve ethnicity or genetic behavioural research – should not be subject to the same strict regime of ethical and scientific review now required of all other researchers who undertake similar studies on like collections of archived biological material and bioinformational resources in the United Kingdom.
- 6.31 **Notwithstanding the fact that the operation of forensic databases falls outside the purview of the Human Tissue Act (2004), we recommend that all research projects involving biological samples collected for forensic use be subject to the same regime of scientific, ethical review and oversight that currently governs access to, and use of, other human biological sample collections in the United Kingdom. This is particularly so in light of the fact that the samples are not sufficiently anonymised (with a link to the datacard still possible after archiving of the sample), and also because none of the individuals whose NDNAD samples are stored has given their consent for their samples to be used for specific research purposes.**
- 6.32 **Further, we would make it an absolute requirement that any NDNAD samples or data provided for research should be irreversibly anonymised (that is, neither the researchers nor the Custodian or any NDNAD staff should be able to relate any result to any named individual). A condition of the release of any biological sample to researchers should be that the researchers would not profile the DNA of any sample. It would be necessary to ensure that, even if the researchers were to do so, they would never be allowed to interrogate the NDNAD to identify the individual with that profile. If such safeguards could not be put in place for a research project, the project should not be permitted.**
- 6.33 It has been argued that biological samples should be subject to stricter security and oversight. The Government undertook during the passage of the Criminal Justice and Police Act in 2001 to give consideration to the suggestion that an independent body be given responsibility for the archives of forensic biological samples. Informed debate about how their custodianship should be organised has yet to materialise, just as there has been little public or political debate over the necessity for the retention of all biological samples on the scale now seen (see paragraphs 4.36–4.56). We consider proposals for wider governance reform in the next chapter.

The storage and analysis of DNA by private companies

- 6.34 The storage and analysis of biological samples is a service that currently three companies provide to police forces¹⁴ although their number is set to rise. Given that biological samples may yield sensitive personal information it is imperative that robust, internationally recognised regulations are in place that prohibit unlawful access to, and unlicensed transfer of, them. Regular audits ensuring that samples or DNA profile databases are not misused are essential (see Chapter 7). **We recommend that organisations and companies that have custody of biological samples complete a standard Material Transfer Agreement, subject to ethical review, that establishes the terms and conditions under which samples may be accessed and used by subsequent recipients.**
- 6.35 The biological samples stored by private companies remain the property of the police force

14. The Forensic Science Service, LGC Forensics Ltd. and Orchid Cellmark.

that submitted them. The subject samples sent by the police to the private companies are accompanied by the individual's 'datacard', which contains the name of the person from whom the sample was taken, and their gender. This is inconsistent with the method of protecting genetic privacy commonly used in medical and other scientific research, namely to de-link stored biological samples from identifying data so that only a very small number of individuals (ideally custodians) have access to both the samples and the identifying data.

- 6.36 Private providers of DNA analysis have all commented that they have no need to retain the 'datacard' that is sent with the subject sample to laboratories, which contains the name of the person from whom the sample was taken, and their gender. These cards are not of use to the company, and yet create the possibility that security and confidentiality of samples could be compromised. **We recommend that datacards should not be provided to private companies. Non-coded identifying details (such as a name) should be removed from the sample as early as possible during the DNA analysis and storage process.**
- 6.37 The provision of DNA analysis by private companies has extended the 'chain of custody' of these biological samples. In addition, the number of providers of DNA analysis is set to increase, stretching present operative and geographic parameters (there is nothing currently to prevent an international company entering the market and, indeed, one of the current providers of DNA analysis has a US parent company). Many of these companies already carry out other genetic analysis for other customers, including the Home Office Immigration Directorate, the Child Support Agency and the Department for Environment, Food and Rural Affairs on the same premises.
- 6.38 It is clear that the forensic analysis of DNA and the retention of biological samples demands the highest operating standards in terms of security, ethical operations and quality. Such standards must not only be reached but also maintained and closely monitored (see Chapter 7). Private companies will, however, also wish to improve upon their processes and procedures, and expand their business opportunities. This may be done by undertaking research on further possible DNA analysis, or on software to interpret DNA profiles, etc.; research that will often necessitate access to information from the NDNAD.
- 6.39 Such requests for 'commercial' purposes require particular scrutiny from the NDNAD Strategy Board, to ensure that research which primarily supports the development of a business opportunity does not gain approval unless fulfilling strict criteria. It is not clear that such strict criteria are currently applied. For example, a research request disclosed in the table of research proposals (see paragraph 6.23) provided by the NDNAD Custodian, for 'access to profile data' from a private company, raises particular questions. It is not evident why the company should seek this access and what information this might include. This is of concern for two reasons. First, the record does not indicate whether this request was approved. Second, it is not clear what data protection or security measures were in place to ensure that staff of the private company could not access identifying information on the profile data and samples, and create an opportunity for misuse.

Emerging and future developments in forensic DNA analysis

- 6.40 There is constant innovation in the technological process of DNA profiling and its uses in support of criminal investigations. The current state of knowledge in these areas is discussed in Chapter 2. Current strands of innovation include:
- methods for the analysis of small and degraded crime scene samples;
 - statistical programmes to assist in the interpretation of mixed samples;
 - the development of devices for speedier processing of crime scene samples, possibly at the

scene itself;

- the analysis of genetic material to reveal a variety of physical characteristics of the originating person; and
- the identification of genetic relatedness.

The Police Science and Technology Strategy 2003 to 2008 makes a commitment to develop ways to 'predict physical characteristics' from DNA. There are obvious advantages for police in being able to refine a target population of suspects for any crime(s). The current state of the technology gives no indication that it is likely to develop quickly. Nevertheless, use of the NDNAD and the analysis of DNA will continue to be refined.

Genetic behavioural research

6.41 There is ongoing research outside the forensic arena, in the area of behavioural genomics, in which researchers seek to identify genetic sequences which, singly or in combination, and in the presence of certain environmental triggers, can impact upon behaviour. The Council's report *Genetics and Human Behaviour: The ethical context* considered that it would be "neither a theoretical nor a practical impossibility to identify genes that contribute to behavioural traits [or] to consider some of the mechanisms by which they do so".¹⁵ However, we cautioned strongly that it is misleading to present this as research that seeks to establish the existence of 'a gene for x' (in this case criminality). Subsequent research has confirmed this view. The complexity of the relationship between genetic, environmental and social factors in the causation of human behaviour is such that individual genes will only very rarely be directly related to a complex behavioural characteristic. The predictive capabilities of tests for any single or small number of genes will, in general, be quite limited.

6.42 Although the notion of a 'crime gene' is simply wrong, forensic DNA databases may still be of use to behavioural geneticists who wish to explore genetic variations influencing behaviours such as novelty seeking or impulsiveness which some believe are linked to criminal or anti-social conduct. Research of this type may extend to include comparative research by racial or ethnic type, in an effort to establish if those variants implicated in particular behaviours appear more or less frequently among members of particular ethnic or racial groups. Such research could, however, have serious implications, including:

- misleading inferences, taking the presence of a sample on the database as indicative of the commission of an offence, or taking the absence or rarity of samples from certain ethnic groups on the NDNAD as indicating a reduced likelihood of their committing an offence;
- the exaggeration of the ability to identify 'causal' variants, leading individuals known to have them to be pre-judged and excluded from services such as education, employment and insurance;
- social stigmatisation and racial stereotyping promoted by a misguided belief that all members of a group are pre-disposed to criminality; and
- denial of social causes (e.g. poverty and poor education) of some types of crime leading to a hardening of attitudes and the abandonment of social policy initiatives.

6.43 Further considerations make the use of NDNAD samples or profiles undesirable as a source of data for such research. The NDNAD does not represent a scientifically valid source of samples for such research, for a number of reasons including:

- the unrepresentativeness of the samples;

15. Nuffield Council on Bioethics (2002) *Genetics and Human Behaviour: The ethical context*. (London: Nuffield Council), pxxii.

- the lack of informed consent;
- the current weakness of oversight;
- the difficulty of finding an appropriate control group; and
- the problems with conducting research that is based on what appear to be robust but could, in fact, be rather fluid categorisations (i.e. 'drug offenders', or 'South Asian').

Interpreting any results in light of these deficiencies and then making generalisations that may well be given wide media coverage on the basis of them would be highly problematic.

6.44 While recognising the potential value of research into genetic behavioural traits and ethnicity, in common with all other non-operational research, proposals in these areas must be subject to robust ethical scrutiny. The scientific credibility of the proposed research must be evaluated, examining, for example, the extent to which inherent biases in the National DNA Database may compromise the ability to identify 'causal' relationships between genetics markers and criminal behaviour and hence support misleading conclusions. Such scrutiny would need to balance any potential benefits from the research against the risks of increasing social stigmatisation and racial stereotyping, or a potential detrimental impact upon efforts to rehabilitate offenders.