

10th November 2008

Dr Peter Mills
NDNAD consultation
Human Genetics Commission
Department of Health
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Dear Peter

Human Genetics Commission consultation on the forensic use of DNA and the National DNA Database

I am pleased to attach a response from the Nuffield Council on Bioethics to the above consultation (Annex A).

In September 2007 the Council published a report, *The forensic use of bioinformation: the ethical issues*. This response is drawn primarily from the conclusions and recommendations made in that report, insofar as they relate to the questions posed in the consultation. A copy of the report is included with this letter.

Paragraph numbers have been provided at the end of each section of the response, in order to indicate from where in the report the recommendations are derived.

I hope that this contribution is useful, and thank you for providing us with the opportunity to comment on this subject. Please do not hesitate to contact us if you require further information or clarification.

Yours faithfully



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Annex A

Human Genetics Commission consultation on the forensic use of DNA and the National DNA Database

Introduction

1. In 2006, the Nuffield Council on Bioethics appointed a Working Group, which included members with expertise in law, genetics, philosophy and social science, to consider the ethical issues raised by the forensic use of bioinformation. As part of the inquiry, the Group held a public consultation, which elicited over 135 responses. These revealed strong differences of opinion as to when biological samples should be taken and when these and DNA profiles should be retained, and the uses to which potentially sensitive genetic information should be put. Views ranged from those who wholeheartedly welcomed the expansion of forensic databases, to those who viewed the increase in police powers with deep suspicion.
2. We put forward our own views and recommendations on these issues, not as the end of the debate, but hopefully as a contribution to the development of well-informed public engagement. We suggested means by which the public interest in crime control can be balanced in a proportionate way with other values such as liberty and autonomy, privacy, consent and equal treatment, and the legal protection of human rights and civil liberties.

Consultation questions

What information should be given to people when a DNA sample is taken following their arrest?

3. We did not comment on the specifics of the information that should be given to people following their arrest. With regards to volunteers, it has been reported that up to 40 per cent of people who voluntarily provide elimination samples also consent to having their sample stored permanently and their profile loaded onto the National DNA Database (NDNAD) where it will be used in speculative searches for the indefinite future.¹ We believe this statistic likely reflects the stressful experience of being involved in a crime and its investigation, and such a level of consent might be lower if the consent were fully informed and properly considered [4.59].

In what way should the National DNA Database be populated?

¹ Joan Ryan MP, House of Commons, Hansard, 9 October 2006, column 492W.

What, if any, profiles, other than those relating to individuals convicted of a criminal offence, should be retained indefinitely (or for periods of many years) on the NDNAD?

In what circumstances, and for what reasons, should DNA (as opposed to the numerical profile derived from it) be retained from individuals whose profiles are recorded on the database?

Profiles and samples of people not charged or convicted

4. The current practice of indefinitely retaining DNA samples and profiles from those not charged or convicted of an offence is expensive and is the focus of considerable public disquiet and mistrust about possible future uses to which the samples might be put. There is, at present, a lack of convincing evidence that the retention of DNA samples and profiles of those not charged with or convicted of an offence has had a significant impact on detection rates and hence it is difficult to argue that such retention can be justified.
5. We recommend that DNA profiles and subject biological samples should be retained indefinitely only for those convicted of a recordable offence. This would bring the law in England, Wales and Northern Ireland into line with that in Scotland. At present, the retention of profiles and samples can be justified as proportionate only for those who have been convicted. In all other cases, samples should be destroyed and the resulting profiles deleted from the NDNAD. We also recommend, however, that independent research should be commissioned by the Home Office to assess the impact of retention. The policy should then be reviewed in the light of the findings of this further research. Our approach is guided by the principle of proportionality, bearing in mind the purpose of retaining the bioinformation on the one hand, and the absence of satisfactory empirical evidence to support the present practice in England, Wales and Northern Ireland on the other.
6. The Scottish practice of allowing retention of samples and profiles, for three years, from those charged with serious violent or sexual offences, even if there is no conviction, should also be followed. Thereafter the samples and profiles should be destroyed unless a Chief Constable applies to a court for a two-year extension, showing reasonable grounds for the extension [4.53-4.55].

Crime scene samples

7. It is reported that since 1995, 121,522 crime scene samples and profiles have been removed from the NDNAD, including 30,589 in 2005/06 alone. These are removed after a conviction has been secured in relation to that offence and a decision has been made that it will no longer be investigated. However, this practice is being re-considered by the NDNAD Strategy Board. Permanent retention of crime scene samples would permit not only the possible identification

of further potential suspects who may have been involved in an offence, but also allow for the possibility of rectifying possible miscarriages of justice in the future. The fallibility of the criminal justice process, and forensic science, remains clearly demonstrated by cases such as that of Damilola Taylor. We therefore recommend that, because crime scene samples are unique and unrepeatable, they must be retained indefinitely [4.56].

Volunteers

8. The permanent retention of samples from victims, witnesses and those invited to volunteer samples was criticised by many respondents to our consultation. The lack of evidence on the efficacy of keeping volunteer samples, and the potential risks and impact upon privacy, lead to questions of necessity and proportionality, and the benefits of keeping such bioinformation 'just in case'. There should also be special consideration when the consent is given by a minor, with an appropriate adult countersigning the consent form. There is a particularly strong case that the minor should be able to revoke the earlier consent upon reaching adulthood. Such considerations also pertain to mentally impaired adults.
9. It is our view that consent given by a volunteer to retain their biological samples and resulting profile on the NDNAD must be revocable at any time and without any requirement to give a reason. This is a basic principle in all medical research and should equally apply to the voluntary component of the NDNAD, as it already does to the Scottish DNA Database. In view of the importance of this principle, we recommend that as a matter of policy, volunteers should not be asked to consent to the permanent storage of elimination biological samples and retention of DNA profiles derived from these samples beyond the conclusion of the relevant case [4.61-4.62].

Minors

10. In our view, the policy of permanently retaining the bioinformation of minors is particularly sensitive in the United Kingdom, where the age of criminal responsibility is low (at age ten years in England and Wales and eight in Scotland) compared with many other countries. There is a separate youth justice system, in recognition of the special protections that should be afforded to children and young persons. The European Convention on Human Rights recognises the special case of children in the criminal justice system. The Supreme Court of Canada, while acknowledging the strong public interest in crime detection, has held that it was contrary to principles of the youth justice system to treat juveniles in the same way as adults, and that juvenile immaturity was a factor which militated against inclusion on the database. Parental consent for sampling would not, in our view, negate concerns surrounding the retention of samples and profiles of minors.
11. When considering requests for the removal of profiles from the NDNAD and the destruction of biological samples taken from minors (including from adults who were minors when the DNA was taken), we

recommend that there should be a presumption in favour of the removal of all records, fingerprints and DNA profiles, and the destruction of samples. In deciding whether or not the presumption has been rebutted, account should be taken of factors such as:

- the seriousness of offence;
- previous arrests;
- the outcome of the arrest;
- the likelihood of this individual re-offending;
- the danger to the public; and
- any other special circumstances [4.71-4.72].

What evidence would be required to demonstrate the 'forensic utility' of the NDNAD (i.e. its value as a tool in the identification and prosecution of criminals)?

12. There is, at present, a lack of convincing evidence that retention of profiles of those not charged with or convicted of an offence has had a significant impact on detection rates and hence it is difficult to argue that such retention can be justified. Statistics about 'matches' to unconvicted people on the Database do not tell us whether these cases actually resulted in a conviction, or whether DNA evidence was essential to the case. We recommend that independent research should be commissioned by the Home Office to assess the impact of retention.

What will be the likely social impact of maintaining the database at current levels or expanding it substantially?

Under what conditions or in what circumstances might arguments for an universal DNA database be persuasive?

13. The Nuffield Council considered the implications of expanding the NDNAD to become a compulsory population-wide database. Some respondents to the consultation suggested that this would be a solution to discrimination and inequalities in treatment posed by a 'criminal' database. There was equally strong support among respondents, however, for the view that such databases should only hold information on those who had been proved to have committed criminal acts. There were broader concerns that such a development would significantly shift the relationship between the individual and the state insofar as it treats all individuals as potential offenders rather than as citizens of good will and benign intent. There would also be increased dangers from 'function creep', given that a population database would be a much more attractive resource to a wide variety of organisations, agencies and corporations.

14. The NDNAD was created to be a forensic database, specifically concerned with collecting data from what the police describe as the 'active criminal population', for no other reason than forensic purposes (or identification of the dead). There would be a need for far more wide-ranging and intensive public debate if a database were to be

established which would extend its remit beyond this group (although some argue that it has already extended beyond active criminals) or beyond forensic purposes. Even those who believe in social solidarity and community obligations may object to a population-wide database on the grounds that, although assisting crime control, it would be seen as a significant step towards an unacceptable 'surveillance society'. Currently, the balance of argument and evidence presented to us is against the establishment of a population-wide forensic DNA database [4.73-4.79].

What governance arrangements are necessary to secure confidence in the acceptable and appropriate management and use of the NDND?

15. The Council made a number of recommendations related to the governance of the NDNAD. These are summarised below.
16. We recommend the development of a clear ethics and governance framework for the operation of the Ethics Group in order to establish:
 - its relationship with the NDNAD Strategic Board;
 - its remit, whether this be to monitor and/or advise or otherwise;
 - its responsibilities for reporting publicly and handling complaints;
 - its powers; and
 - how it is to maintain its independence.
17. Further consideration should be given to broader ethical oversight and governance in respect of the umbrella role of the Forensic Science Regulator [7.25]
18. At present, the 'exceptional circumstances' criteria for removal of records from the NDNAD and other databases are too restrictive, and the Chief Constable's discretion too wide. If the current system remains and records are not automatically removed for those not convicted, in accordance with our earlier recommendations, we recommend that:
 - There should be public guidelines explaining how to apply to have records removed from police databases, and the grounds on which removal can be required.
 - The police should be required to justify the need for retention in response to a request for removal of an individual's records (with a strong presumption in favour of removal in the case of minors).
 - An independent body, along the lines of an administrative tribunal, should oversee requests from individuals to have their profiles removed from bioinformation databases. The tribunal would have to balance the rights of the individual against such factors as the seriousness of the offence, previous arrests, the outcome of the arrest, the likelihood of this individual reoffending, the danger to the public and any other special circumstances [7.37].
19. We recommend, not only that there must be robust procedures for assessing applications for research access to the NDNAD and stored samples, but that there should also be a requirement to articulate

publicly the basis upon which applications for any access to data stored on bioinformation databases will be considered and the precise purposes for which access will, and will not, be granted either to police or non-police agencies [7.32].

20. We recommend that there should be a statutory basis for the regulation of forensic databases and retained biological samples. A regulatory framework should be established with a clear statement of purpose and specific powers of oversight delegated to an appropriate independent body or official. This should include oversight of research and other access requests, for example for further testing of samples or familial searching and inferring ethnicity. We are pleased to see the establishment of an Ethics Group by the Home Office, with a remit to oversee the running and uses of the NDNAD, but its specific functions and powers must be more clearly, and publicly, articulated. Moreover, we consider that a longer-term view is required that considers the future possibilities and challenges that may come with increased access and linkage involving a range of forensic databases [7.55].

21. We recommend a far greater commitment to openness and transparency and a greater availability of documents to public scrutiny. Where public access is denied for reasons of security and the administration of justice, this should be fully explained and justified. Efforts to improve the generation of data and statistics are welcomed, as are apparent efforts to increase the publication of data. These moves are still in their early stages, and their continuation is strongly supported [7.57].

What further uses might it be appropriate to make of the genetic information collected for the NDNAD in the future?

22. 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.

23. The Council considered three further uses of the genetic data collected for the NDNAD: familial searching, ethnic inferencing and research:

- *Familial searching*

While we do not believe that familial searching interferes with privacy rights to an extent that should prohibit its use, 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 [6.11].

- *Ethnic inferencing*

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 [6.17].

- *Research*

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 [6.31].

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;
- whether the research has been subject to adequate levels of scientific and ethical review;
- the outcomes of research [6.21-6.25].

Are there circumstances in which it might be acceptable for information contained on the NDNAD to be shared or linked, perhaps anonymously, with other agencies or databases?

24. We recommend, on the basis of standard European data protection principles, a minimum set of safeguarding requirements to consider before allowing access to bioinformation databases to international law enforcement agencies, which would be:

- to ensure there is a sufficient level of data protection in all authorities/agencies that would receive information;
- to subject each request to adequate scrutiny as to merit and reasonableness and on a transparent basis;
- to agree the criteria for sharing data, for example only for the investigation of serious crimes or in special circumstances; and
- to share only as much information as is necessary to meet the request and only to those authorities or agencies which 'need to know' [7.42].

25. The threshold for holding DNA profiles on a forensic database is far lower in the United Kingdom than in any other Member State of the EU, and the proportion of the population included on the UK DNA Database is correspondingly far higher than in other EU countries. The Government should as a matter of urgency examine the implications of DNA exchanges for those on the UK NDNAD. The Government should insist on the inclusion in the Prüm Treaty of provisions to ensure that its operation is properly monitored. At the very least, the following is required:

- an obligation on national agencies to produce annual reports, including statistics, on the use of their powers under the Treaty; and
- an obligation on the European Commission to produce an overall evaluation of the operation of the Treaty, for submission to the European Council, the European Parliament and national parliaments, to see whether it needs amendment [7.52].