

This response was submitted to the consultation held by the Nuffield Council on Bioethics on the Forensic use of bioinformation: ethical issues between November 2006 and January 2007. The views expressed are solely those of the respondent(s) and not those of the Council.

Dr Rob Elles on behalf of the British Society for Human Genetics

**British Society for Human Genetics
Response to the consultation paper
Forensic use of bioinformation: ethical issues
Nuffield Council on Bioethics**

The BSHG represents health professionals working in specialised genetic services and medical research (www.bshg.org.uk). Medical Genetic practice shares technologies with forensics especially DNA marker technologies used in identity testing.

This consultation is timely coming at a time when there is much debate about the surveillance of citizens by the State, as new technologies to generate, store and process bioinformation start to be applied and as parallel uses of the same technologies in medical research and applied medicine become more mainstream.

The questions posed in the consultation are relevant and comprehensive. However the document does not consider the links between the bio-information data bases currently serving the needs of the criminal justice system and the electronic records of biometrics which will form part of the proposed identity card and passport systems.

Collections of DNA and data from patients and their relatives held in Regional Genetic Centres and Genetic screening laboratories

Blood samples from neonates are stored in screening laboratories for almost all persons born in the UK since 1980. In addition Medical Genetic departments in the UK have been collecting DNA with the informed consent of patients and their relatives since the mid 1980s. It is considered good practice to retain these collections for at least 30 years.¹

They are estimated to comprise samples from 1-1.5m UK citizens. Samples from between 80,000 and 120,000 individuals per year are added to these collections.² In addition Medical Genetic departments have accurate and extensive records of family relationships on at least the same number of individuals.

The legal framework for obtaining, storing analysing and sharing these collections and medical data derived from them was extensively reviewed by the Joint Committee on Medical Genetics in 2006. The recommendations from this document reflect and form a base-line for good practice in this area.³

This response was submitted to the consultation held by the Nuffield Council on Bioethics on the Forensic use of bioinformation: ethical issues between November 2006 and January 2007. The views expressed are solely those of the respondent(s) and not those of the Council.

The Human Tissue Act created an offence of non consensual analysis of DNA where the intention is prurient or malicious. The offence applies only to the holding of cellular material with the intention of DNA analysis without consent and does not apply to the holding and use of extracted DNA.

Release of clinical material or data requires consent from the individual concerned or an order from the court and guidelines for healthcare workers in these circumstances have recently been produced by the Royal College of Pathologists and the Institute for Biomedical Sciences.⁴ From consultation with BSHG members we are aware of only one attempt by the police, or representatives of the prosecution or defence to access Medical Genetic materials or records. However the human genetics community are concerned that rules to access medical tissue and DNA collections have not been considered. BSHG members voiced their concern that the relationship between health professionals and their patients and their relatives would be damaged by access to these collections for the purposes of criminal justice in all but the most exceptional circumstances.

Medical implications of forensic data

The consultation raises the possibility that the forensic use of bio-information could result in the revelation of sensitive personal or medical information from DNA. This is unlikely to be a feature of the application of the standard marker panels currently in forensic use. However this will emerge if the standard technology evolves towards application of a very large panel of markers comprising single nucleotide polymorphisms. These markers will carry data on associations with both common and rare medical conditions which may be predictive or diagnostic of health status including mental health status. In addition the discovery of medical information from a DNA based test on an individual may have implications for their blood relatives. In Medical Genetic practice this may generate a duty to inform relatives of their risk from an inherited condition. These aspects of the medical implications of forensic data should be considered as part of the oversight of research using forensic collections of biological material and the development of the forensic use of these technologies.

Oversight of research use and applications of collections of tissue and bio-information.

Some BSHG members voiced an opinion that the ethical oversight of research and the use of materials and data in forensic collections should be consistent with the mechanisms and standards applicable to medical research and practice.

1. The retention and storage of pathological records and archives; guidance from the Royal College of Pathologists and Institute for Biomedical Science. 2005 <http://www.rcpath.org/resources/pdf/>

2. One Regional Centre has collected a total of 112,000 individual samples since 1985 representing approximately 25,000 samples per million from the population it serves. Allowing for duplicates held in more than one centre samples from between 1 and 1.5m individuals are estimated to be held in the UK.

3. Consent and confidentiality in genetic practice – guidance on genetic testing and sharing genetic information Joint Committee on Medical Genetics 2006.

[http://www.bshg.org.uk/documents/official_docs/Consent_and_confid_corrected_21\[1\].8.06.pdf](http://www.bshg.org.uk/documents/official_docs/Consent_and_confid_corrected_21[1].8.06.pdf)

4. Guidelines for the release of specimens and data to the police and other law enforcement agencies Royal College of Pathologists and Institute for Biomedical Science 2006. <http://www.rcpath.org/resources/pdf/>