





# 1st Annual Report of The Ethics Group: National DNA Database

April 2008



## FOREWORD



It is a pleasure to be introducing the first report of the [Ethics Group: National DNA Database](#). The Group was formed in July 2007 and had its first meeting in September 2007. The report is an account of its work and the recommendations made between then and April 2008.

Since the early 1990s the use of DNA analysis as a forensic tool has been led by the UK but in parallel with its success in crime detection, there have been increasing concerns about possible discrimination and the invasion of privacy. There have also been questions about the need to retain derived data, the

manner in which DNA is obtained and international intelligence sharing. Inevitably ethical conflicts have arisen and the debate has gradually intensified.

The Ethics Group seeks to balance the interests of public protection through the forensic use of DNA with the inevitable invasions of privacy and personal labelling that this causes. There are no absolutely right answers. The approach taken by the Group has been to try to develop logical algorithms which are evidence based and in which each step is clearly set out so that it can be seen how we have reached our conclusions. This allows those who disagree to see the deductive thread and demonstrate where we have assumed a false premise or have applied the wrong proportionality.

The activities of the Group have led us to believe that there is considerable confusion and misinformation in the public domain not only about forensic DNA itself but also about how the UK arrived at the present situation. Because of this, the report, as appropriate, includes information on the statutory and operational matrix within which DNA is taken and processed for forensic purposes.

The report makes 11 recommendations and sets out the work plan for the coming year. The Group presents these for consideration in good faith that they will clarify the present uncertainty around certain issues, not weaken effective policing for the protection of society, and rebalance some aspects of the relationship between the individual, the criminal justice system and the state.

Finally, I would like to thank all those who have collaborated with us and given freely of their time: they are mentioned in the text in the relevant sections. If I have forgotten anybody or any organisation I can only apologise in advance. If others, having read this report would like to give us their views, we would be pleased to hear from them.

A handwritten signature in black ink, appearing to read 'Peter Hutton'.

**Prof. Peter Hutton**

Chair, [Ethics Group: National DNA Database](#)

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## SUMMARY

On 25 July 2007, Meg Hillier MP, Parliamentary Under-Secretary of State at the Home Office tabled a Written Ministerial Statement announcing the setting up of **The Ethics Group: National DNA Database** as an Advisory Non-Departmental Public Body. The purpose of the Ethics Group is to advise Ministers on ethical issues concerning the National DNA Database (NDNAD) and related matters. This is to include ethical aspects of:

- Services provided, and techniques employed, by approved suppliers of DNA profiles to the NDNAD, comprising those currently provided and employed, and proposals for new services and techniques;
- Applications for research involving access to NDNAD samples or data;
- Other matters relating to the management, operation and use of the NDNAD;
- The Ethics Group may also, at the request of Ministers, conduct inquiries into other ethical issues relating to scientific services provided to the police service and other public bodies within the criminal justice system.

In the discharge of its functions the Ethics Group may undertake inquiries:

- At the request of Ministers;
- At the request of the NDNAD Strategy Board;
- On its own initiative.

The Ethics Group comprises a Chair and 11 Members and has met 3 times since its formation. Based on its own discussions, the concepts of privacy and freedom from discrimination (as set out in human rights legislation), and soundings from other stakeholders, the work of the Ethics Group has, to date, been directed towards:

- The classification and management of volunteer DNA samples;
- The process of taking consent for a DNA sample given voluntarily;
- Information for the public, the police, volunteers, and custodial subjects on forensic DNA;
- The security and identification of DNA samples and profiles;
- The custom and practice within which the NDNAD operates and the role of Chief Constables;
- The need for, and value of, a 'universal' NDNAD;
- The ethical aspects of research applications to work on data stored on the NDNAD.

In this report, The Ethics Group makes the following recommendations for consideration:

**Recommendation A:** There needs to be a better and more transparent classification of DNA profiles and samples which are provided voluntarily: public understanding of the term 'voluntary sample' would benefit from a closer definition and separation into specific categories.

**Recommendation B:** For those members of the public who are believed to be innocent at the time of sampling and voluntarily donate their DNA to help the police with their enquiries, the presumption should shift to an expectation that these samples will be used only for the case under investigation, that the profile will not be loaded onto the NDNAD, and that the samples and all data derived from them will be destroyed when the case has ended.

**Recommendation C:** There should be a specific consent form for competent adults who are not suspected of the crime under investigation when they agree to give a volunteer DNA sample.

**Recommendation D:** The consent form enclosed in Appendix C, Annex 1 is proposed as a template for the purposes of Recommendation C.

**Recommendation E:** There is an urgent need for better information for the public, the police, volunteers and custodial subjects on the use and limitations of forensic DNA analysis. Where relevant, this should accompany the sampling process.

**Recommendation F:** The identification and process control of DNA samples and profiles should be reviewed with a view to ensuring that confidentiality and individual privacy are preserved as far as possible and within clear controls

**Recommendation G:** A clearer, simpler and less cumbersome process needs to be put in place to enable those who wish to appeal against the decision of a Chief Constable to retain their DNA profile on the NDNAD.

**Recommendation H:** Consideration should be given to reviewing the definition of 'exceptional circumstances' and ensuring that the reasons for the retention of data and samples are aligned with data protection legislation, human rights legislation and the concept of proportionality.

**Recommendation I:** Consideration should be given to further public clarification of the role of the NDNAD and reinforcement of the message that it is intended only to be used for criminal intelligence.

**Recommendation J:** Consideration should be given to formally announcing publicly that the NDNAD will only be used for the currently described purposes (i.e. criminal intelligence) and will never transform into a repository for the whole nation's DNA characteristics.

**Recommendation K:** The ethics application form set out in Appendix C, Annex 2, should be accepted as a suitable template by the NDNAD Strategy Board

# 1. INTRODUCTION

- 1.1. DNA analysis is one of the most powerful forensic tools available for the prevention, detection and prosecution of crime. The UK is a world leader in this technology and the establishment of a National DNA Database<sup>1</sup> (NDNAD) for England and Wales in 1995 was a world first. Scotland and Northern Ireland have their own DNA databases but also submit samples to the NDNAD.
- 1.2. Prior to 2001, section 64 of the Police and Criminal Evidence Act 1984 (PACE), as amended by the Criminal Justice and Public Order Act 1994, specified that if a person was neither charged nor convicted of an offence for which they had been arrested, any DNA sample and the data derived from it had to be destroyed. Following difficulties with the admissibility of existing DNA evidence, section 82 of the Criminal Justice and Police Act 2001 changed this requirement and allowed the police to retain DNA samples and profiles for future use. Subsequently, Section 10 of the Criminal Justice Act 2003 amended PACE to allow the police to take a DNA sample from anybody arrested for a recordable offence<sup>2</sup> and detained at a police station regardless of the outcome of the case. This DNA and the data derived from it can only be used for purposes relating to preventing and detecting crime, investigating an offence, conducting a prosecution or identifying a deceased person or a body part. A £240 million DNA Expansion Programme (April 2000 – March 2005), aimed at gathering the DNA profiles of all known 'active offenders', resulted in a significant expansion of the size of the NDNAD and the number of retained samples.
- 1.3. Since the establishment of the NDNAD in 1995, there have also been legislative changes relating to the retention of human tissue, data protection and human rights. DNA technology has progressed rapidly, competitive tendering has been introduced into the public sector, DNA databases have been established in other countries and there is an increasing awareness of the benefits of international co-operation.

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1 National DNA Database is a registered trademark

2 These are offences which are recorded on the Police National Computer to form part of the person's criminal record and include most offences other than traffic offences.

- 1.4. Superimposed on these events, a parallel public interest developed in the possible infringements of equality, privacy, and individual rights and freedoms from the use of forensic DNA technology and the retention of DNA profiles and samples by the Criminal Justice System (CJS). Such concerns, usually regarding the relationships between the individual, society and the state, have found a legal foundation within the Human Rights Act since it came into force in October 2000.
- 1.5. As a result of all these factors, the NDNAD gradually came under increasing public scrutiny and for some years the Human Genetics Commission (HGC) argued the need for a source of independent ethical advice in relation to its use. This was supported by other interested parties such as the Nuffield Council on Bioethics. In addition, there have been, (and continue to be), many Parliamentary Questions in relation to the NDNAD and its operation. Subsequently, following:
- a recommendation from the 2005 Report of the Commons Science and Technology Committee<sup>3</sup>, and
  - a written Ministerial Statement by Andy Burnham MP, Parliamentary Under-Secretary of State at the Home Office, in February 2006, in which he announced that the Government was considering setting up such a Group
- the provisional Terms of Reference and *modus operandi* of an Ethics Group were drawn up and recruitment for the Chair and Members of the Group began in March 2007.

## 2. APPOINTMENT OF THE CHAIR AND MEMBERS OF THE GROUP

- 2.1 The appointment to all posts was by open competition following public advertisement. The process was overseen by the Appointments Commission and the recommended candidates were appointed by Home Office Ministers.
- 2.2 The Chairman, Peter Hutton, was the first post to be appointed in May 2007. He, together with the Interim Forensic Science Regulator and representatives of the Appointments Commission then interviewed and recommended names to the Minister for the other members of the Group.
- 2.3 Two sets of interviews were undertaken. The first took place in June 2007 and 8 names were recommended. Although these provided a very good balance of the kind of skills and experience the Group needed, the Chairman and the Advisory Appointments Panel were concerned that:
  - none of the successful candidates was able to be clearly identified as bringing a publicly demonstrable knowledge and experience of dealing with issues of particular relevance to the young, those in black and minority ethnic (BME) communities and religious diversity, and
  - there was no appointed member with expert knowledge of genetics.
- 2.4 At the first meeting of the Ethics Group in September 2007 it was agreed that:
  - the former of these gaps should be filled by open recruitment for one or two additional members against this particular specification and
  - that the latter should be filled by co-option of an individual known to have expertise in this area.
- 2.5 Subsequently interviews were carried out in January 2008 and two further names were recommended to Ministers. Professor Stephen Bain was co-opted for his expertise in genetics and understanding of the ethical issues surrounding the NDNAD.

The current membership of the Ethics Group stands as follows with biographies at Appendix A:

Chairman: Professor Peter Hutton

Members: Mrs Julia Ayetey  
Professor Stephen Bain  
Dr Derrick Campbell  
Mrs Wendy Coates  
Ms Madeleine Colvin  
Mr Michael Menlowe  
Dr Jane Pearson  
Dr Clive Richards  
Dr Sameer Sarkar  
Ms Sarah Thewlis  
Dr Suzy Walton

## 3. THE TERMS OF REFERENCE AND METHODOLOGY OF THE GROUP

### Description

3.1 **The Ethics Group: National DNA Database** was set up as an Advisory Non-Departmental Public Body. On 25 July 2007, Meg Hillier MP, Parliamentary Under-Secretary of State at the Home Office tabled a Written Ministerial Statement announcing its creation 'to provide Ministers with independent ethical advice on the operation and practice of the National DNA Database (NDNAD) and related issues'.

The protocol governing the working of the Group provides that:

- i). Its role is to provide independent advice to Ministers;
- ii). It will comprise a chairperson with up to ten appointed members plus co-opted members;
- iii). It will be supported by staff in the Forensic Science Regulation Unit;
- iv). Its costs will be met by the Home Office within affordability constraints;
- v). Its Chair will have a seat on the NDNAD Strategy Board;
- vi). Any formal reports will be submitted to Ministers, through the Home Office.

The full Protocol can be found as Appendix B

### Remit

- 3.2 The purpose of the Ethics Group is to advise Ministers on ethical issues concerning the NDNAD. This is to include ethical issues relating to:
- Services provided, and techniques employed, by approved suppliers of DNA profiles to the DNAD, comprising those currently provided and employed, and proposals for new services and techniques;
  - Applications for research involving access to NDNAD samples or data;
  - Other matters relating to the management, operation and use of the NDNAD.
  - The Ethics Group may also, at the request of Ministers, conduct inquiries into other ethical issues relating to scientific services provided to the police service and other public bodies within the criminal justice system.

## Operation

- 3.3 In the discharge of its functions the Ethics Group may undertake inquiries:
- At the request of Ministers;
  - At the request of the NDNAD Strategy Board;
  - On its own initiative.
- 3.4 The Ethics Group may, of its own volition, undertake inquiries in relation to matters falling within its remit if a simple majority of the Group resolves in favour of doing so. In the case of a tie, the Chair will have a casting vote.
- 3.5 The Ethics Group will normally aim to meet at least quarterly, and otherwise as agreed by the membership.
- 3.6 Support for the Ethics Group will be provided by the Home Office. No budget is delegated to the Group but such assistance as is reasonably required to enable the Group to undertake its duties will be provided, within available resources.
- 3.7 A member of the Home Office Senior Civil Service will be appointed as Sponsor for the Group. This is currently Andrew Rennison, the Forensic Science Regulator. The Sponsor will appoint a Committee Secretary, with responsibility for planning and arranging meetings, setting agendas in consultation with the Ethics Group Chair; ensuring that papers are prepared and circulated on time and in good order; minuting meetings and assisting members in the discharge of their functions.
- 3.8 Appointment to the Ethics Group is for a period not exceeding three years: this may be renewed for a second term of up to three years by mutual consent of the Minister and the appointee and subject to a satisfactory appraisal.

## Reporting

- 3.9 By the end of April each year, the Ethics Group will submit to Ministers a report on its work during the preceding year.
- 3.10 Where the Ethics Group is invited to advise Ministers on a particular issue, or where the Group decides to undertake an inquiry of its own volition, it will submit a report to the Minister through the Home Office Sponsor. The response will be provided by the Minister after due consideration of the recommendations.
- 3.11 Where the Ethics Group is invited to advise the NDNAD Strategy Board on a particular issue, it will submit a report to the Board, with a copy to the Minister, through the Home Office Sponsor. Any response will be provided by the Board, unless the Minister is minded to intervene.

- 3.12 In the interests of public accountability, the Ethics Group will carry out its work as openly as possible, within the terms of the Code of Practice on Access to Government Information, subject to any conditions set by Ministers, or agreed by the Group. Meetings of the Group will not normally be open to members of the public, but notes of its meetings will be published, subject to any redactions considered to be necessary. Reports produced by the Group will be published at Ministerial discretion.

## **Conduct**

- 3.13 Members of the Ethics Group are required to observe the Seven Nolan Principles of Public Life endorsed by the Committee on Standards in Public Life and to comply with the contents of the published Protocol.
- 3.14 Each member must at all times act in good faith and observe the highest standards of impartiality, integrity and objectivity in relation to the conduct of the Committee's business.

## 4. THE MEETINGS AND ACTIVITIES OF THE GROUP

### Meetings

4.1 To date, the Ethics Group has met 3 times:

- 3<sup>rd</sup> September, 2007
- 13<sup>th</sup> December, 2007
- 13<sup>th</sup> March 2008

Between meetings, work and discussion proceeded through electronic, postal and telephone communication. Some sub group work has also been conducted via smaller meetings.

After each meeting, the agreed notes of the meeting have been published on the Home Office website without any redactions. Copies of these appear in Appendix C.

### Activities

4.2 From its inception, members of the Ethics Group felt it appropriate to make contact with groups and individuals who had an interest in the forensic use of DNA and the NDNAD. The value of this was:

- To get information on the key concerns of those making comments;
- To establish the views of other regulatory bodies on the operation of the NDNAD;
- To establish links for possible future collaborations;
- To let interested parties know of the existence, terms of reference and methods of working of the Ethics Group.

4.3 Accordingly, the Chairman and other members of the Group have met with:

- Genewatch;
- Justice;
- Sir Alec Jeffreys (the inventor of DNA profiling);
- The Police Powers and Protection Unit (a Unit within the Home Office);
- Liberty;
- The Nuffield Council on Bioethics;
- The Wellcome Trust;

- The Forensic Science Service Ltd;
- Lord Justice Sedley (correspondence only);
- The Human Genetics Commission (HGC);
- The Information Commissioner;
- The Conservative Party Shadow Home Secretary;
- The National Policing Improvement Agency (NPIA);
- The Equality and Human Rights Commission;
- Action on Rights for Children.

4.4 At all meetings the Ethics Group representatives have been well received and the role and remit of the Ethics Group was welcomed. Following each meeting a letter was sent from the Chair to the stakeholder(s) summarising the issues discussed and confirming the main points the stakeholder would like to see addressed. It was agreed that this *modus operandi* should be adopted as standard practice following a first meeting with stakeholders. There are further stakeholder meetings planned. .

### **Attendance at other meetings**

- 4.5 The Chairman and/or other members of the Ethics Group have also attended or had meetings with:
- The NDNAD Strategy Board;
  - The Forensic Science Committee;
  - Volunteer DNA processes workshops;
  - The NDNAD Custodian;
  - The NDNA Think Tank on Equality Impact Assessment;
  - The National Policing Improvement Agency
  - The NPIA Advisory Panel;
  - The Forensic Science Regulator;
  - Ethics in Policing Portfolio Working Party.

## **Presentations and evidence**

The Chairman has made presentations in his role as Chair of the Ethics Group as follows:

- 3<sup>rd</sup> December 2007 to the Police Strategic Command Course
- 23<sup>rd</sup> January 2008 to the Forensic Science Regulator Stakeholder Conference
- 30<sup>th</sup> January 2008 to the House of Lords Select Committee on the Constitution
- 25<sup>th</sup> February 2008 to the Citizen's Inquiry (reporting to the HGC)

## 5. WORK PROGRAMME AND RECOMMENDATIONS

### Work programme since September 2007

5.1 Based on its own discussions, the concepts of privacy and freedom from discrimination (as set out in human rights legislation), and the soundings taken from the interested parties listed above (4.3 & 4.5), the work of the Ethics Group has been directed towards:

- The classification and management of volunteer samples;
- The process of taking consent for a DNA sample given voluntarily;
- Information for the public, the police, volunteers, and custodial subjects on forensic DNA;
- The security and identification of DNA samples and profiles;
- The custom and practice within which the NDNAD operates and the role of Chief Constables;
- The need for, and value of, a 'universal' NDNAD;
- The ethical aspects of research applications to work on the NDNAD.

In all these deliberations, the Group has been careful to note the importance of not reducing the effectiveness of policing in the protection of society.

### The classification and management of volunteer DNA samples

5.2 'Volunteer samples' is a term that covers all DNA samples and derived profiles used by the police that have been taken from persons who have not been arrested at the time of sampling. Within the CJS it is a generic label used to embrace a range of sample origins covering situations such as:

- Mass screening (which will eliminate many but may produce a suspect),
- Voluntary entry onto the DNA database by former sex offenders and those who live in areas of endemic crime (for the purposes of them being able to achieve early elimination from suspicion when innocent);
- Samples taken from the presumed innocent to assist with the identification of contaminant DNA at crime scenes.

The use of a single designation for this wide variety of sample origins is simultaneously opaque and confusing to the public. The term 'voluntary sample' would benefit from closer definition and separation into specific categories.

5.3 The Group reviewed the work that ACPO (Association of Chief Police Officers) had been progressing on the value and management of samples taken from volunteers. The Chair also attended some ACPO meetings on this subject and two ACPO documents were considered by the Group: these were

- the report of a Volunteer DNA Process Workshop held jointly by ACPO and the Home Office and
- a report presented to the NDNAD Strategy Board on the value of volunteer samples in November 2007.

5.4 Importantly, the work presented to the DNA Strategy Board illustrated that DNA matches between volunteer profiles and crime stains are satisfactorily achievable irrespective of whether or not the volunteer profiles are loaded from the analysing laboratory to the NDNAD. With the exception of sex offenders (who are sometimes sampled under the volunteer procedure), on the results to date, all of the matches useful to the police would have been obtained without speculative searching of the NDNAD. There would therefore be no loss to operational policing if, for the majority of crimes, volunteer samples were not loaded onto the NDNAD and were used only in relation to the investigation of the crime for which they were obtained.

5.5 Having weighed the pros and cons of the situation, and bearing in mind that:

- Individuals have rights to privacy under human rights legislation;
- Since September 2006, Section 45 of the Human Tissue Act 2004 (HTA) has strengthened the rights of individuals over the use and testing of their own body tissues;
- Other than for 'excepted purposes' (as defined in the HTA), without express consent it is a criminal offence to possess a person's bodily material with the intent to obtain a DNA profile;
- The goodwill of the public needs to be fostered;
- Operational policing would not be put at risk;
- There are significant cost savings from not storing DNA samples indefinitely,

the Ethics Group concluded that in the taking and use of volunteer DNA samples, the **normal presumption** should be:

- That these samples will be used only for the case under investigation;
- That the profile will not be loaded onto the NDNAD; and,
- That the samples and all data derived from them will be destroyed when the case has ended.

Any exceptions to this would need a strong and evidence-based rationale.

**Recommendation A:** There needs to be a better and more transparent classification of DNA profiles and samples which are provided voluntarily: public understanding of the term 'voluntary sample' would benefit from a closer definition and separation into specific categories.

**Recommendation B:** For those members of the public who are believed to be innocent at the time of sampling and voluntarily donate their DNA to help the police with their enquiries, the presumption should shift to an expectation that these samples will be used only for the case under investigation, that the profile will not be loaded onto the NDNAD, and that the samples and all data derived from them will be destroyed when the case has ended.

## The process of taking consent for a DNA sample given voluntarily

- 5.6 The police need consent to take DNA from the various classes of 'volunteer' (see Sec 5.2) who have not been arrested but whose DNA would be helpful to police enquiries. At present, a 'volunteer' signs a consent form on which they agree either:
- For the sample to be used just for that investigation; or,
  - For it to be loaded onto the NDNAD and retained indefinitely (where it would be subject to speculative searching).
- 5.7 These two options are one below the other on the same piece of paper and there is one consent form for all classes of volunteer. If the volunteer does not give permission for retention and loading onto the NDNAD, the profile and the sample are held in the analysing laboratory on its own database for comparison to crime stains from that specific enquiry and destroyed when the case is closed.
- 5.8 For the consent of the volunteer to be valid:
- It is essential that the consequences of selecting which option to sign are made clear to them by the person taking the consent;
  - The information to make that decision must be in a format, level of complexity and language that the individual can understand;
  - The individual must be given the opportunity to ask any reasonable questions.
- 5.9 The Group reviewed the current volunteer DNA consent form for England and Wales and the one for Scotland. For comparison, documents published by the Department of Health relating to the requirements for taking informed consent for clinical procedures were studied. Following discussion, it was concluded that the process of consent provided by the current consent form with two consent options closely positioned (one for not loading onto the NDNAD and the other for loading and retention), no 'user-friendly' supporting information

and a potential lack of consistency in the knowledge of the person taking the sample falls short of reliably meeting the requirements for consent, so obtained, to be valid.

- 5.10 In approaching this issue, it was decided to recognise that there were different classes of potential volunteer (as currently defined), and in the first instance to limit our considerations to competent adults in whom:
- A DNA sample would help the police; and,
  - Who were not under suspicion of the criminal offence being investigated at the time of sampling.
- 5.11 It was recognised that some volunteers will be minors or vulnerable adults. These will be considered in the future.
- 5.12 A competent adult voluntarily donating a tissue sample is contributing to the public good and, in so doing, is entitled to certain rights and privileges and is outside the 'excepted purposes' defined in Part 3, Section 45 of the Human Tissue Act 2004. Because at the time of DNA donation it is a voluntary act implying consensual testing, the donating individual has the right to determine the uses to which the sample would be put and should not lose the right to withdraw consent in the future. The Human Rights Act also gives them certain rights of privacy. Whilst it was noted that in law consent can be verbal and does not have to be written, it was considered that in the case of volunteer DNA sampling the situation was such that only written consent is appropriate.
- 5.13 On the basis of this background, the Group concluded that a satisfactory and equitable relationship between the volunteer and the CJS should include:
- An understanding that the *intent* in taking the volunteer sample is to help the police by providing information which will either eliminate the volunteer from suspicion or identify DNA which is an innocent contaminant at a crime scene<sup>4</sup>;
  - The provision of information on DNA profiling in a manner which the volunteer can readily understand, together with the volunteer having the opportunity to ask questions about the process;
  - Time for the volunteer to consider the implications of what is being requested;
  - A clear understanding that the DNA profile and sample will be used only for the investigation for which it is provided and that at the end of the investigation the sample, profile and any other information derived from it will be destroyed;
  - An assurance that the profile will not be loaded onto the NDNAD or be subject to speculative searching;

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<sup>4</sup> If a volunteer subsequently becomes a suspect and is arrested, then they would automatically lose their privileges of volunteer status and fall under the legislation in the CJS.

- The ability of the volunteer to withdraw the whole or part of their consent for the use of their DNA at any time;
- The provision for the volunteer to provide a DNA profile without retention of the DNA sample;
- Specific permission to use the sample as part of a research project.

5.14 Discussion concluded that to meet these criteria, a specific consent form must be used for a volunteer sample (as defined in 5.10 & 5.13 above): if a person were to become a suspect and was then arrested, a second sampling procedure should be undertaken. There should be no conversion of the existing volunteer consent: to mix volunteer and CJS samples was seen as potentially confusing to both the consent process and the classification of stored data.

5.15 Bearing all these considerations in mind, the volunteer consent form proposed by the Ethics Group (which is intended for legally competent, English-speaking adults) is shown at Appendix C, Annex 1. It should be noted that on the form, the section for signing consent is integral with that containing the questions and answers on the sampling process, subsequent analysis and retention. Instructions for taking copies, translating into languages other than English, providing translators etc., are not provided on the form. Such detail is considered to be part of the process that would be automatically followed before the adopting of any documents by law enforcement agencies. The Group wishes to place on record the need to ensure that information used during the process of taking consent is presented in a manner appropriate to the understanding of the volunteer and answers any questions they might ask.

**Recommendation C:** There should be a specific consent form for competent adults who are not suspected of the crime under investigation when they agree to give a volunteer DNA sample.

**Recommendation D:** The consent form enclosed in Appendix C, Annex 1 is proposed as a template for the purposes of Recommendation C.

### **Information for the public, the police, volunteers, and custodial subjects on forensic DNA**

5.16 The Ethics Group agreed that it had a responsibility for making sure the public, the police and those from whom DNA was sampled had access to good information on DNA profiling and its implications. Public information is also an important issue for the stakeholders surveyed. A trawl was undertaken of published and electronically available information in the public domain on DNA and DNA profiling. The conclusion of the Group was that the information which currently exists on DNA (some of which is very high quality), does not meet the specific needs of DNA profiling and the informed consent process i.e. there was no 'off the shelf' information base that could be recommended or readily adapted for the purposes of the Group's work.

- 5.17 **For the public.** Some public information sheets were drafted, but it was felt that more discussion was needed on the content, standard and targets of such information before they could be progressed. Particular points of discussion were the level of understanding in the public, the number of first languages in use in the UK and the possible routes of communication (electronic, public libraries, leaflets etc). Also, although it was clearly a part of the Group's ethical responsibilities to make sure that such information was available, it was noted that it was not necessarily its role to produce it.
- 5.18 **For the police.** Although not to be considered a generalisation, the Group inferred that on some occasions the CJS representative taking the consent and DNA sample might demonstrate limited knowledge of the implications of, and knowledge about, DNA profiling. Furthermore, there seemed little continuity or standardisation across the English and Welsh police forces on how training in this area was being delivered. The Group accepted that the actual technical exercise of taking the DNA sample was simple but it considered that the act of taking consent from volunteers was much more demanding and impinged on requirements in both criminal and civil law. It recognised that the two events of consent and sampling might be conducted sequentially by separate individuals, but the Group was clear for the need of the person taking consent to be appropriately informed and able to answer any reasonable questions put to them by the donor. There has been a preliminary discussion about this with the NPIA and the Group plans to return to this issue.
- 5.19 **For volunteers.** Information is a critical part of informed consent. Some very simple, basic information is included on the reverse side of the proposed consent form (see Recommendation D) to meet what are judged to be the concerns of a 'typical' English-speaking adult. In addition there will however, need to be information available to meet the variations in levels of understanding and the detail requested by volunteers.
- 5.20 **Custodial subjects.** Even though the law allows a sample to be taken from a person in custody against their will, there is still a moral responsibility to give them information. Some people in custody will be neither charged nor convicted and may be found to have no connection with the crime for which they were arrested. Information developed for volunteers would probably be satisfactory for this purpose.

**Recommendation E:** There is an urgent need for better information for the public, the police, volunteers and custodial subjects on the use and limitations of forensic DNA analysis. Where relevant, this should accompany the sampling process.

## The security and identification of DNA samples and profiles

- 5.21 The Human Rights Act 1998 recognises that all persons, whatever their civil or criminal status have rights to their privacy: DNA profiles and samples are no exception to this principle. The holding of personal data is also covered by data protection legislation. Once a DNA sample has been taken it has to be packaged, labelled, transferred to the laboratory, analysed, reported, and re-linked with the correct individual's record. Some of this process relies on the human accuracy of transcription and some on electronic coding. At present, on some occasions, to reduce the possibility of error, the system transfers DNA samples to analysing laboratories with both an anonymous bar code and a paper record which carries personal identifying information.
- 5.22 The Ethics Group concluded that both volunteers and those required to provide a DNA sample under the CJS are entitled to expect confidentiality and privacy with respect to the details of the sample provided and the information derived from it. Knowledge of the link between the personal details of the person and the anonymous bar code on the sample and the derived profile must comply with a strict 'need to know' principle. A useful analogy was drawn between this situation and that of medical records being subject to Caldicott Guardianship and legislation through the PIAG system<sup>5</sup>.
- 5.23 Given the present government policy to encourage competition within the private sector and hence to 'out-source' aspects of the forensic services to commercial organisations (whose staff appointments are outside the immediate controls of the CJS), the Ethics Group concluded that the methods of anonymising and tracking DNA samples needed to be reviewed with considerable urgency. There is a need for clarity of process and well defined oversight and guardianship of sample identification. The Ethics Group considered that this might possibly lie outside the CJS with the NDNAD Custodian or another appointed authority, dependent on the Custodian's scope and remit following the current review of forensic regulation. The Ethics Group was strongly of the view that there should be clear regulations stating who, or what organisation, should have knowledge of the link between the personal details of the person donating the sample and the bar code used during testing and storage. This applied to both volunteer and CJS samples: the rights of privacy still deserve respect after arrest, charging and conviction.

**Recommendation F:** The identification and process control of DNA samples and profiles should be reviewed with a view to ensuring that confidentiality and individual privacy are preserved as far as possible and within clear controls.

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<sup>5</sup>The Patient Information Advisory Group (PIAG) was established to provide advice on issues of national significance involving the use of patient information and to oversee arrangements created under Section 60 of the Health and Social Care Act 2001.

## The custom and practice within which the NDAND operates and the role of Chief Constables

- 5.24 The Criminal Justice Act 2003 made provision for the police to take a DNA sample without consent from all persons arrested for a recordable offence and detained at a police station. As far as could be ascertained by the Chair, there is no compulsion on the police to take such a sample, although custom and practice is such that this is now routine. Similarly, there is no compulsion on the police to load the profile of a custodial sample, once taken and processed, onto the NDNAD, but again, this is now routine. The DNA Expansion Programme (2000 – 2005) aimed at gathering the DNA profiles of all known 'active offenders' supported the routine of sampling and retention and greatly increased the size of the NDNAD.
- 5.25 Operational police policy for the taking of DNA samples for offences which are non-recordable depends on the policing policy of each force, and can only be taken with the formal consent of the suspected offender. This situation has not been considered by the Ethics Group.
- 5.26 In the case of a volunteer DNA sample, as described in section 5.6, at present, the individual can sign a consent for the sample to be used just for that investigation, or can consent for it to be loaded onto the NDNAD and retained indefinitely (where it would be subject to speculative searching). If the volunteer profile is loaded onto the NDNAD and the sample retained, then it is not possible for the volunteer, if they subsequently change their mind, to get the profile removed or the sample destroyed. Once loaded, the law removes the rights of the individual to revoke their voluntarily given consent.
- 5.27 The difficulty of removal also applies to those arrested but not charged or convicted. For their profile to be removed from the NDNAD and the sample destroyed, the individual has to apply to the Chief Constable who 'owns' all the DNA profiles and samples originating in his or her jurisdiction. The policy is that requests are only acceded to if there are 'exceptional circumstances'. These circumstances are not defined in law but are the subject of nationally written guidance. If such a request is not granted because the circumstances are deemed not to be exceptional (which is usually the case) there is no simple or readily available mechanism (either within or independent of the CJS), through which an individual can challenge the decision. This process has resulted in the S & Marper case proceeding through the High Court to the European Court of Human Rights from which a judgement is currently awaited.
- 5.28 Individually identifiable personal information held on non-personal databases is potentially a breach of privacy under Article 8 of the Human Rights Act 1998. For such information to be held, it must be:
- 'In accordance with the law' ;
  - 'Necessary in a democratic society in the interests of national security, public safety or the economic well-being of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of rights and freedoms of others'.

5.29 In order to determine whether or not an intrusion into personal privacy is legitimate and proportionate to the need, a policy maker is obliged to adopt a three stage process and ask the following questions:

- Is there a legitimate aim to the interference?
- Is the interference prescribed by a clear and accessible law?
- Is the interference proportionate to the identified legitimate aim and is it necessary in a democratic society?

5.30 The areas of concern identified by the Ethics Group with the current operation of the NDNAD are:

- Although the objectives and use of the NDNAD and stored DNA samples have a basis in legislation, there is no proper statutory footing for, and oversight of, its operation;
- The discretion of Chief Constables to define the 'exceptional circumstances' under which DNA profiles and samples may be deleted and destroyed is potentially inconsistent and discriminatory and contrary to an individual's privacy rights. Currently, there is the possibility for regional variation in decision-making in respect of what should be a nationally standardised process and it is unclear when lawfully permitted intrusions on a person's privacy are allowed;
- The requirements of the Human Rights Act given above which allow intrusion into an individual's privacy appear not to be met by current custom and practice;
- Within the present arrangements there is an understandable concern of the invasion of their privacy by some people who have been arrested but never charged nor convicted;
- The possibility of international data sharing and its regulation by international treaty needed careful consideration;
- There are issues of data protection which are complex and appear not to have been explored.

**Recommendation G:** A clearer, simpler and less cumbersome process needs to be put in place to enable those who wish to appeal against the decision of a Chief Constable to retain their DNA profile on the NDNAD.

**Recommendation H:** Consideration should be given to reviewing the definition of 'exceptional circumstances' and ensuring that the reasons for the retention of data and samples are aligned with data protection legislation, human rights legislation and the concept of proportionality.

## The need for, and value of, a 'universal' NDNAD

- 5.31 The Criminal Justice and Public Order Act 1994 (amending PACE 1984) gave powers to the police to take body samples and for the 'checking' against 'other samples or the information....contained in records held by or on behalf of the police or held in connection with or as a result of an investigation of an offence'. The later 2001 Criminal Justice and Police Act specifically restricted the use of DNA samples to 'purposes related to the prevention or detection of crime, the investigation of an offence or the conduct of a prosecution'. All other civilian uses (e.g. paternity testing) are prohibited<sup>6</sup>. In this way the NDNAD became established as an intelligence database for use by the CJS: it contains records not only of those guilty of committing crimes but also those of the uncharged, the unconvicted and 'volunteers'.
- 5.32 The Ethics Group is aware of suggestions (made in public by several individuals) that to prevent discrimination between individuals and ethnic groups it would be fairer to have the whole of the population on the Database.
- 5.33 A discussion by the Ethics Group took place which considered the relevant factors and took into account issues of privacy, fairness, equality and ethnicity. Key points which emerged were:
- The reasons for taking and retaining DNA samples and profiles are defined in legislation (as above). The Group believes that the spirit of the original law in 1994 was **not** that the NDNAD should become a database containing the details of the whole population;
  - Although there are arguments that can be made for the establishment of a national, civilian, non-criminal DNA database, they are very different from those used for the establishment of a crime-related intelligence database;
  - A database containing the DNA profiles of all the supposed inhabitants of the United Kingdom at any one time would in fact never absolutely do so in practical terms. There would for example, be those who would avoid profiling (by illegal means or on the grounds of human rights), temporary visitors, migrant workers, and the deliberate submission of false identities;
  - Despite the existing legislative controls, there are unknown and unpredictable social consequences of being potentially able to identify the parentage and sibling status of all individuals. The ramifications extend beyond the discovery of unexpected birth relationships to inheritance rights and the penetration of genetic traits.

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<sup>6</sup> The only permitted exception to this (established in legislation as a modification within the Serious Organised Crime and Police Act 2005 following the aftermath of the South East Asian tsunami in 2004), is for the identification of deceased persons who happen to be on the NDNAD by chance.

- 5.34 Consequently, it is inappropriate without public debate and fraught with ethical and social problems and questions of personal freedom, to allow a criminal intelligence database to convert into a national repository of the nation's DNA characteristics. Arguing that the database should be expanded to include all the population, (the majority of whom will never commit a crime), to prevent inequality and discrimination is, on balance, unsustainable when issues of proportionality and personal privacy are taken into account.
- 5.35 Further support for this viewpoint comes from the results of the study (see section 5.4 above) which demonstrated that there would be no loss of policing effectiveness if volunteer samples were not loaded onto the NDNAD. Also, there are huge cost and practicality implications for proposing a government financed profile registry and national sample depository (this line of inquiry has not been followed by the Group to date).

**Recommendation I:** Consideration should be given to further public clarification of the role of the NDNAD and reinforcement of the message that it is intended only to be used for criminal intelligence.

**Recommendation J:** Consideration should be given to formally announcing publicly that the NDNAD will only be used for its currently described purposes (i.e. criminal intelligence) and will never transform into repository for the whole nation's DNA characteristics.

### **The ethical aspects of research applications to work on the NDNAD**

- 5.36 At the request of the NDNAD Strategy Board, the Group reviewed the ethical aspects of research applications for work on the existing database and stored samples. Following discussions and by comparison with the ethical components of medical ethics application forms, the proposed format of a new NDNAD Ethics Research Application Form for consideration by the NDNAD Strategy Board is given in Appendix C, Annex 2.

**Recommendation K:** The ethics application form set out in Appendix C, Annex 2, should be accepted as a suitable template by the NDNAD Strategy Board.

## 6. FUTURE WORK PLAN

The future activities of the Ethics Group are partly dependent upon the response to this report, requests for specific studies that may be forthcoming from the Minister, the NDNAD Strategy Board and other interested parties, and the availability of resources. The workload falls into 4 broad categories:

### 6.1 Category 1: Responsibility for completed recommendations

If the recommendations in this report are adopted by the Minister and the NDNAD Strategy Board, the Ethics Group has a responsibility to work with the NDNAD Strategy Board, the NPIA, the Forensic Science Regulator, the Home Office and any other necessary agencies to ensure implementation. The Group has not yet discussed how it would embrace this role or the resource implications of doing so.

### 6.2 Category 2: On-going work related to existing recommendations

There is a need to complete existing work on volunteer consent for the following groups:

- Those who are minors at the time of sampling;
- Adults who do not have the capacity to give independent consent.

### 6.3 Category 3: New questions to be asked

New questions of an ethical nature, when posed, need to be in a form that:

- If the appropriate evidence base can be defined and established;
- Will allow further resolution of the conflicts between the individual and the state by application of the concepts of privacy, equality, anti-discrimination and proportionality.

Such questions for consideration over the next year are as follows:

- Why is there a disproportionate spread of ethnic origins between the general population and those persons on the NDNAD? Are there discriminatory processes that need to be corrected?
- Is it ethically right that all research on existing DNA samples and profiles on the NDNAD be limited in the immediate future to the non-coding section of the genome?
- Is there an ethical case for destroying any remaining volunteer DNA when a satisfactory profile has been obtained?
- Is it ethically defensible for the CJS to retain the DNA profiles and samples of those persons who have been arrested but not charged?
- What are the cost-benefits to, and the ethical implications for, the CJS and/or the individual (whether a volunteer or CJS subject) in retaining a second DNA sample when a satisfactory profile has been obtained?

- Is it unethical and disproportionate not to apply the General Rules for Criminal Record Weeding on Police Systems<sup>7</sup> to DNA profiles and samples?

**6.4 Category 4: Maintaining a watching brief, and where appropriate, a contribution to, relevant on-going proceedings which impact on the use and retention of DNA profiles and samples**

Currently, these are as follows:

- The PACE review and the statutory framework within which the operation of DNA sampling, analysis, storage, retention and oversight occurs;
- The relevance of data protection legislation to DNA profile and sample retention and storage;
- The outcome of the *S & Marper* case from the ECHR;
- The developing international perspective on forensic DNA and the implications of the Prüm Treaty.

**6.5 Delivery target to April 2009:** Subject to the availability of resources (and following discussions with the Minister, the NDNAD Strategy Board, the Forensic Science Regulator and the Custodian), it would be the objective of the Ethics Group within the next 12 month period to:

- Conclude work implied in Categories 1 & 2 above
- Provide recommendations on most of the questions posed in Category 3 and make substantial progress on the others;
- Contribute and respond to, as required, developments issues in Category 4.

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<sup>7</sup> As published by ACPO

## APPENDIX A: BIOGRAPHIES OF THE ETHICS GROUP MEMBERS

### **Professor Peter Hutton** PhD, FRCA, FRCP, FIMechE

Following an initial career in mechanical engineering and bioengineering research, Peter qualified in Medicine in 1978. Since 1986 he has been Professor of Anaesthesia at the University of Birmingham and Honorary Consultant at the University Hospital, Birmingham. From 2000 – 2003 he was President of the Royal College of Anaesthetists and from 2002 – 2004 was Chairman of the Academy of Medical Royal Colleges. He is also a Fellow of the Institution of Mechanical Engineers and a Chartered Engineer.

Over the years he has contributed to a number of committees and working parties for the Department of Health and the NHS and served on several public bodies. He has acted as an external consultant in clinical governance for NHS organisations and as an assessor for the National Clinical Assessment Service.

Peter has been a member of the General Medical Council, and is currently the Independent Consultant Member of the Prescription Medicines Code of Practice Appeal Board and Vice-chair (Medical) of the Long Term Conditions Alliance. In 2007 he was appointed as a member of the Bar Standards Board.

### **Julia Selman-Ayetey** BA, MPhil, GDL

Julia has a master's degree in Criminology from the University of Cambridge and has also been called to the Bar of England and Wales.

She has a longstanding academic interest in the application of DNA in criminal justice systems around the world. During her time in Cambridge, her thesis reviewed the role of DNA profiling in the British Criminal Justice System. She has since published a number of articles and book chapters on the subject.

Having worked as a Research Fellow at the University of East London, Julia is currently a Visiting Tutor at King's College London where she teaches criminal law. She also continues to work with and mentor young offenders.

### **Professor Stephen Bain MA, MD, FRCP**

Steve undertook his undergraduate pre-clinical training at St John's College, Cambridge and following clinical training at King's College Hospital, London qualified in medicine in 1983. He went on to hold junior appointments in London, the East Midlands, and the West Midlands. His research has centred on the genetics of type 1 diabetes, and for a time he held a Medical Research Council Lectureship.

In 1993, Steve was appointed as a Senior Lecturer/Honorary Consultant Physician at Birmingham Heartlands Hospital, became a Fellow of the Royal College of Physicians in 1996 and was promoted to Reader in Diabetic Medicine at Birmingham University in 1998. His current interests include the genetics of diabetic nephropathy, hypertension and the provision of diabetes services within the community.

Steve sits on the Human Genetics Commission and is a lay member of the NDNAD Strategy Board. He was appointed to the newly created Chair in Medicine (Diabetes) in Swansea University in 2005 and practices diabetes and general medicine in Swansea NHS Trust.

### **Dr Derrick Campbell DMS, MBA, PhD, FCMI**

Derrick is the Chief Executive of the Race & Equality and Community Cohesion Council in Sandwell and was previously the CEO of the Sandwell Division of the Black Country Chamber of Commerce. He is the Chairman of 'Wise-Up', a project that he started in 1997, which works with vulnerable and disaffected school children, encouraging them to value themselves and to be the best they can be.

Derrick is also chair of the National Independent Advisory Group on the Criminal Use of Firearms and the chair of Birmingham Reducing Gang Violence, an independent advisory group working with West Midlands Police, Birmingham City Council and the Probation Services.

Qualified originally as an electrical engineer, he is also a Fellow of the Chartered Institute of Managers, and speaks regularly in public and in the media on equality, race and diversity issues. Derrick is an ordained Christian Minister, a student of Black History with a PhD in philosophy and history from Liverpool University and the author of a number of articles and books.

## Wendy Coates JP

Until 1998, Wendy was a civil servant who, at various times, was a Member of the Cabinet Office Equal Opportunities Training Network, a Training Manager in Equal Opportunity and Customer Service and Policy Officer at the Department of Social Security.

Wendy joined Thames Valley Police Authority in 1999 and was Vice-chair of the Authority when she left in 2007. Here she led on Diversity Issues from 2000 and in 2002 was a member of the Stephen Lawrence Steering Group, chaired by the Home Secretary. This group subsequently became the Police Race and Diversity Learning and Development Programme Board and in March 2007 she received a Command Unit Commendation for her work with the Community of Berkshire East and the Police. She also represented the Association of Police Authorities on the Skills for Justice and Home Office consultation groups on the Disability Discrimination Act guidance.

Wendy has expertise in many aspects of diversity and equality and has been a special constable and a volunteer probation officer. She is currently a Magistrate who sits in Hounslow.

## Madeleine Colvin

Madeleine is a qualified barrister specialising in human rights law. Over the past 20 years she has gained extensive experience of law reform and policy formation whilst working for several key non-governmental organisations including Liberty and JUSTICE.

Madeleine has previously advised the Department for International Development, been a member of the Home Office Expert Group advising on the human rights implications of access to communications data and has been an adviser to HM Inspector of Prisons. She is the author of several publications on human rights issues, including EU co-operation in criminal matters.

Madeleine presently combines being a part-time Immigration Judge with practising as a trained mediator specialising in disability discrimination cases. She also undertakes a broad range of work as a Human Rights Consultant covering activities such as human rights training for Turkish military judges to convening and chairing a women's international human rights law course at the Centre for the Study of Human Rights at the London School of Economics in London. She specialises in privacy issues including all forms of surveillance.

## **Michael Menlowe**

Michael lectured in philosophy at a number of universities, most recently, the University of Edinburgh. His special interests are in moral philosophy and the philosophy of law. Until his retirement, he was Head of the School of Philosophy, Psychology and Language Sciences at the University of Edinburgh. Following his retirement from full-time teaching, he chairs Fitness to Practice Panels for the General Medical Council and is a member of the Scottish Committee of the Administrative Justice and Tribunals Council. Michael is a Trustee of the Scottish Refugee Council and a lay member of the Royal College of Pathologists.

## **Dr Jane Pearson BA, PhD**

Jane originally is the Lead Research Management and Governance Manager for the Greater Manchester Comprehensive Local Research Network (GMCLRN), which is one of 25 CLRNs set up in late 2007. Her role is to facilitate good quality research in the NHS and to streamline the process of approval within a framework that recognises the rights of patients and the public yet also encourages innovation.

Jane has been involved in clinically based research for over 15 years in both NHS and University environments and this involvement gave rise to her interest in ethics and equality and diversity issues. Her own research (leading to a PhD) has involved the monitoring of cerebral function in critically ill patients, a situation where consent is often difficult. Until December 2007 she served on the North West Multi-Centre Research Ethics Committee, latterly as the Vice- Chair.

## **Dr Clive Richards MBChB, FRCGP, FFPH**

Clive is a Consultant in Public Health Medicine at Nottinghamshire County Teaching Primary Care Trust. Previously he worked as a general practitioner in the NHS for 13 years before taking additional training in public health medicine and becoming Director of Public Health for Rushcliffe Primary Care Trust (till October 2006). During this time he continued to undertake some clinical work in primary care in an economically deprived part of Nottingham. He is a teacher of undergraduate and postgraduate students in public health and is a Lecturer in Public Health at the University of Nottingham.

Clive has a special interest in the ethical foundations of prioritising and rationing and the fair allocation of restricted resources. He has led on screening for Greater Nottingham, is Chair of Nottingham Hospitals Ethics of Clinical Practice Committee and is a member of the Department of Health Committee on the Ethical Aspects of Pandemic Influenza.

Clive is an Associate of the General Medical Council and a member of their Fitness to Practice Panel. He is a Board Member of Nottingham YMCA.

### **Dr Sameer Sarkar MD, LL.M, MRCPsych, ABPN Inc**

Sameer is a Consultant Forensic Psychiatrist who undertook postgraduate training in the UK and the USA. He is registered for specialist practice in both countries.

He has studied law at Harvard Law School and Northumbria University and holds an LL.M. With a long-standing interest in the interface between law and ethics he has researched into mental health law and the limits of coercion. He teaches ethics at two of London's medical schools, since 2002 has been a member of the Royal College of Psychiatry's (RCP) Ethics Committee and was a member of their Law Committee from 2002-2006.

Sameer has published widely on professional ethics and is an advisor to the government and regulatory bodies on professional boundary violations. He is an RCPsych College Tutor and an examiner for both the RCPsych in the UK and The American Board of Psychiatry and Neurology, Inc in the USA. He is also an associate of the General Medical Council, sits on the GMC's Fitness to Practice Panels (FTP), and is a PMETB partner.

### **Sarah Thewlis BA, MPhil, FCIPO, FRCGP(Hon)**

Sarah began her career as a graduate trainee in human resources (HR) with Marks & Spencer plc. and became the Divisional Personnel Controller for Distribution Centres. From 1991-1994 she was Deputy Secretary at the Royal College of Physicians, involved in HR, facilities management, Council work and IT, and from 1994-2002 was Chief Executive at the Royal College of General Practitioners, the professional body for GP's with a membership of over 19,000.

Since 2002 Sarah has been the Chief Executive and Registrar of the Nursing & Midwifery Council (NMC), the regulatory body for Nurses and Midwives with a register of 682,000. The core function of the NMC is to establish standards of education, training, conduct, performance and ethics for nursing and midwifery and to ensure that those standards are maintained; thereby safeguarding the health and wellbeing of the public.

In working with healthcare professionals for over 15 years, Sarah has acquired a good lay understanding of the principles of research and genetics and has just completed an MPhil in medical law and ethics.

### **Dr Suzy Walton** PhD, CPsychol, CSci, CDir

Suzy is a chartered scientist, chartered occupational psychologist and chartered director, and has been a Senior Civil Servant working in central government for over a decade. From 2000-2003 she led strategic futures work in the Prime Minister's Strategy Unit. More recently she has served in the Prime Minister's Delivery Unit. From 1996-2000 she was a military psychologist in the Ministry of Defence.

Suzy has a PhD in Applied Psychology (studying suicide in military personnel), and works as a non executive director for several public interest organisations including Birmingham Children's Hospital and the Council for the Registration of Forensic Practitioners. She also sits on the National Specialist Commissioning Group (which purchases treatment for rare diseases) and was a lay member of the professional conduct committee for the General Council of the Bar from 2000-2006.

Her earlier career was as a producer, editor and presenter for Sky News, LBC Radio and the BBC. She is also a Governor of the University of Westminster.

# APPENDIX B: PROTOCOL GOVERNING THE ETHICS GROUP: NATIONAL DNA DATABASE

## Status

1. The Ethics Group for the National DNA Database (NDNAD) is an advisory Non-Departmental Public Body (NDPB) established under the authority of the Secretary of State for the Home Office, who is answerable to Parliament for the performance of the Committee.

## Remit

2. The purpose of the Ethics Group is to advise Ministers on ethical issues concerning the NDNAD. This is to include ethical issues relating to:
  - Services provided, and techniques employed, by approved suppliers of DNA profiles to the DNAD, comprising those currently provided and employed, and proposals for new services and techniques;
  - Considering applications for research involving access to NDNAD samples or data;
  - Other matters relating to the management, operation and use of the NDNAD.
3. The Ethics Group may also, at the request of Ministers, conduct inquiries into other ethical issues relating to scientific services provided to the police service and other public bodies within the criminal justice system.

## Composition

4. The Ethics Group will comprise a Chair and up to ten members who shall be recruited through open competition via the public appointments process. The Chair of the Ethics Group shall, ex officio, be appointed to membership of the NDNAD Strategy Board.
5. The Chair may, in consultation with the Home Office Sponsor and with Ministerial approval, invite other individuals to serve on the Group for limited periods of time where additional skills, knowledge or experience are required.
6. The Chair may, in consultation with the Home Office Sponsor and with Ministerial approval, appoint one of the members of the Ethics Group to deputise for him or her in his or her absence.
7. The Chair and members of the Ethics Group will serve in accordance with the terms and conditions appended to this Protocol. Appointment to the Ethics Group will be for a period not exceeding three years: this may be renewed for a second term of up to three years by mutual consent of the Minister and the appointee and subject to a satisfactory appraisal.

## Operation

8. In the discharge of its functions the Ethics Group may undertake inquiries:
  - At the request of Ministers;
  - At the request of the NDNAD Strategy Board;
  - On its own initiative.
9. The Ethics Group may, of its own volition, undertake inquiries in relation to matters falling within its remit if a simple majority of the Group resolves in favour of doing so. In the case of a tie, the Chair will have a casting vote.
10. The Ethics Group will normally aim to meet at least quarterly, and otherwise as agreed by the membership.
11. Support for the Ethics Group will be provided by the Home Office. No budget is delegated to the Group but such assistance as is reasonably required to enable the Group to undertake its duties will be provided, within available resources.
12. A member of the Home Office Senior Civil Service will be appointed as sponsor for the Group. The Sponsor will appoint a Committee Secretary, with responsibility for planning and arranging meetings, setting agendas in consultation with the Ethics Group Chair; ensuring that papers are prepared and circulated on time and in good order; minuting meetings and assisting members in the discharge of their functions.

## Reporting

13. By the end of April each year, the Ethics Group will submit to Ministers a report on its work during the preceding year.
14. Where the Ethics Group is invited to advise Ministers on a particular issue, or where the Group decides to undertake an inquiry of its own volition, it will submit a report through the Home Office Sponsor. Ministers will respond to the Ethics Group following such further inquiries, or the seeking of such advice, as may be required.
15. Where the Ethics Group is invited to advise the NDNAD Strategy Board on a particular issue, it will submit a report to the Board, with a copy to the Minister, through the Home Office Sponsor. Any response will be provided by the Board, unless the Minister is minded to intervene.
16. In the interests of public accountability, the Ethics Group will carry out its work as openly as possible, within the terms of the Code of Practice on Access to Government Information, subject to any conditions set by Ministers, or agreed by the Group. Meetings of the Group will not normally be open to members of the public, but minutes of its meetings will be published, subject to any redactions considered to be necessary. Reports produced by the Group will be published at Ministerial discretion.

## Conduct

17. Members of the Ethics Group are required to observe the Seven Principles of Public Life endorsed by the Nolan Committee on Standards in Public Life and to comply with the contents of this Protocol. The Nolan Principles are set out in the Appendix detailing the terms and conditions of the members.
18. Each member must at all times act in good faith and observe the highest standards of impartiality, integrity and objectivity in relation to the conduct of the Committee's business. In particular, members should:
  - i). familiarise themselves with the terms of reference of the Committee;
  - ii). undergo any required induction training;
  - iii). declare any personal, professional or business interest which may, or may be perceived (by a reasonable member of the public), to influence their judgement. This should include, as a minimum, personal direct and indirect pecuniary interests, and should normally also include such interests of close family members and of people living in the same household. A register of interests will be kept up-to-date and will be open to the public;
  - iv). not participate in the discussion or determination of matters in which they have a personal or business interest, and should normally withdraw from the meeting (even if held in public) if their interest is direct and pecuniary;
  - v). make a declaration of interest at any Ethics Group meeting if it relates specifically to a particular issue under consideration, for recording in the minutes (whether or not a member of the Group withdraws from the meeting);
  - vi). not misuse information gained in the course of their public service for personal or professional gain or for political purposes, nor seek to use the opportunity of public service to promote their private interests or those of connected persons, firms, businesses or other organisations;
  - vii). not hold any paid, or high-profile unpaid, posts in a political party, and not engage in specific party political activities on matters directly affecting the work of the Ethics Group. When engaging in other political activities, members should be conscious of their public role and exercise proper discretion; and
  - viii). understand and accept that they are appointed as individuals and not as representatives of organisations by which they are employed or with which they have significant contacts.

19. The Chair has particular responsibility for providing effective leadership to the Ethics Group and for:
- i). ensuring that the Group meets at appropriate intervals, and that the minutes of meetings and any reports to the Secretary of State accurately record the decisions taken, and where appropriate, the views of individual members;
  - ii). representing the views of the Group to Ministers;
  - iii). representing, where appropriate, the views of the Group to the general public;
  - iv). ensuring that new members are briefed on appointment; and
  - v). sitting on the panel which advises Ministers on new appointments and re-appointments.
20. Any Ethics Group member has the right to bring to the attention of Ministers any matter, which he or she believes raises important issues relating to his or her duties as a member. In such cases the member should, before approaching Ministers, raise their concerns with the Chair to establish whether they might be resolved within the Group.

### **Liability and confidentiality**

21. Provided that a member of the Ethics Group acts honestly, reasonably, in good faith and without negligence in the conduct of the Group's business, the member will not have to meet out of their own personal resources any personal civil liability which is incurred in execution or purported execution of their duties.
22. Members of the Ethics Group may, however, be held personally liable if, in the performance of their duties, they knowingly make a fraudulent or negligent statement, which results in a loss to a third party. They may also commit:
- i). a breach of confidence under common law; or
  - ii). a criminal offence under insider dealing legislation.

if they misuse information gained through their position on the Ethics Group.

23. In accepting appointment to the Ethics Group, members are required to accept that they will not disclose any information or documents if they are marked with any GPMS security classification (including RESTRICTED) or the content of any discussions relating to such information, without the approval of the Chair. Members also undertake not to make copies of any such documents, and to follow the advice provided by the Chairman and Secretariat about the handling of such documents.

## APPENDIX C: NOTES OF THE ETHICS GROUP MEETINGS

### Note of the NDNAD Ethics Group first meeting held at 1pm on Monday 3rd September 2007 at Wellington House, Birmingham

#### Present:

Peter Hutton	NDNAD Ethics Group Chairman
Wendy Coates	NDNAD Ethics Group member
Madeleine Colvin	NDNAD Ethics Group member
Andrea Jane Pearson	NDNAD Ethics Group member
Sameer Sarkar	NDNAD Ethics Group member
Suzy Walton	NDNAD Ethics Group member

#### Apologies

Michael Menlowe	NDNAD Ethics Group member
Clive Richards	NDNAD Ethics Group member
Sarah Thewlis	NDNAD Ethics Group member

#### In attendance

Keith Batten	Home Office, FSRU (Secretariat)
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### Item 1: Oral introduction from the Chairman

1. Peter Hutton welcomed those present to the NDNAD Ethics Group first meeting.

### Publishing minutes

2. It was agreed that the work of the NDNAD Ethics Group should be as transparent as possible and notes of meetings should be made available to the public. The notes should show the background to an issue and the NDNAD Ethics Group's decision. Comments should not be attributed to an individual member of the NDNAD Ethics Group and it should not be possible to identify individual cases under discussion.

## Relationships with related bodies such as the Human Genetics Commission (HGC)

3. The meeting noted that the HGC had been supportive of the creation of the NDNAD Ethics Group. Two members of the HGC had sat on the NDNAD Strategy Board. Links with the HGC were beneficial to the work of the NDNAD Ethics Group and should be developed.

4. There was discussion about:

- offering a seat on the NDNAD Ethics Group to a member of the HGC or another individual in their own right and in the light of their personal experience of the relevant issues. It was noted that the Chair had authority to co-opt individuals with relevant experience or expertise. Full membership (including “voting rights”) could only be exercised by those appointed under the Office of the Commission for Public Appointments (OCPA) rules.
- developing relationships with other relevant bodies such as the Commission for Racial Equality (CRE), Liberty GeneWatch etc. and representation of the NDNAD Ethics Group at meetings with other organisations.
- obtaining understanding from the youth, faith and black & minority ethnic community and the need of the NDNAD Ethics Group to visibly represent all sections of the community. It was noted that there was a pressing need to include representation from these constituencies on the Ethics Group.

5. The NDNAD Ethics Group agreed:

- the Chairman should offer a co-opted place on the NDNAD Ethics Group to Steve Bain for one year in the first instance, in his own right rather than as a member of the HGC in the light of his experience on the NDNAD Strategy Board, and his knowledge of genetics and DNA

**Action: Peter Hutton**

- relevant bodies such as the CRE, Liberty and Genewatch etc should be contacted to explore areas of common interest. Ideally, there should always be two members of the NDNAD Ethics Group attending meetings with other relevant bodies

**Action: Peter Hutton**

- an advert should be placed, under OCPA rules, to fill the two vacancies on the NDNAD Ethics Group. The advert should seek to appoint individuals with experience of BME, faith and young peoples’ issues

**Action: Secretariat**

## Item 2: The NDNAD Ethics Group protocol: NDNADEG/030907/01

6. It was noted that all members of the NDNAD Ethics Group had received, signed and returned their copy of the protocol.
7. There was discussion about:
  - paragraph 3 of the protocol which allowed for extension of the NDNAD Ethics Group's remit, at Home Office Minister's request and/or discretion, to deal with ethics issues not related to the NDNAD.
  - paragraph 13 which required the NDNAD Ethics Group to produce its first annual report on 1 April 2008.
  - paragraph 16 which called for the NDNAD Ethics Group to work as openly as possible and to publish minutes of meetings.
8. The NDNAD Ethics Group:
  - noted the protocol.

## Item 3: Existing ethical issues: NDNADEG/030907/02

9. The NDNAD Ethics Group reviewed the paper prepared and looked to establish a work plan for the forthcoming year.
10. There was discussion about:
  - (i) Volunteer samples
11. The Chair reported that he had attended a recent meeting on volunteers' samples. It was acknowledged that the progression of this issue was likely to be complex. It was noted that when taking consent for medical procedures, clearer and more explicit consent forms were used. Whilst such situations could be used as possible vectors for change, it was noted that on all occasions, it might not be possible to have a direct read across to consent for criminal justice system purposes.
12. The NDNAD Ethics Group:
  - agreed a document should be drafted, in consultation with ACPO and other stakeholders, which would seek to explore all relevant issues in connection with:
    1. whether the police should retain volunteers' samples
    2. whether the police should automatically load volunteers' samples
    3. what information volunteers needed in order to make an informed decision on the taking and use of samples (mindful that they were volunteers' and not suspects' samples)
    4. consent arrangements for partially sighted or non English speakers
    5. how the consent forms satisfied the Plain English campaign
    6. what was required to satisfy the Human Rights Act & Human Tissue Act
    7. arrangements for the removal of volunteers' samples

8. handling the small number of volunteers who may wish their samples loaded in order to evidence that they were no longer offending (the example of reformed sex offenders was given)
  9. informing the Minister on any need to change the status of volunteers' samples
13. A general point was made that information on DNA sampling for the general public was not easy to find in a 'user-friendly' format and that the Ethics Group has an unambiguous responsibility to help the public to make informed decisions.

**Action: Peter Hutton**

## (ii) Removal of loaded samples

14. All new volunteer samples were only loaded onto the database after a consent form had been signed. There was an issue about demonstrating that informed consent had actually been obtained and in handling volunteer samples already on the database. It was noted that removals were only made for "exceptional reasons" and on the authority of a Chief Constable.
15. Reference was made to the police elimination database. This database held DNA samples of those who joined the police service since 2003 as well as those in post pre 2003 who had provided a DNA sample voluntarily.
16. It was noted that the Police and Criminal Evidence Act review had also raised the issue of the removal of volunteers' samples<sup>8</sup>. ACPO had been asked by the Group to provide a report on the value of volunteer samples in the investigation of crime. The NDNAD Ethics Group might wish to consider making a formal response.
17. Requirements under Article 8 of the Human Rights Act were explored, particularly evidencing the need for volunteers' samples. This had particular relevance to juveniles and crime victims and their loading onto the NDNAD. There was a request for more information on the value that volunteer samples had had in the solving of subsequent crimes. The Chairman confirmed that he had requested this information from a member of the NDNA Strategy Board.
18. The NDNAD Ethics Group further agreed:
  - to review the ethics of the process for handling the identification and tracking of samples and the process for their addition and removal from the database, mindful that the process should be uniform across England and Wales
  - to consider whether a joint project with the NDNAD Strategy Board should be initiated to review the process for removing samples
  - to identify (for comparison purposes) and further develop the ethical arguments for when and why a Chief Constable should authorise removal of a sample

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<sup>8</sup> Secretary's Note: The PACE Review focuses on police powers to take DNA samples from arrested persons and does not specifically invite comments on samples taken from volunteers.

- to review the implications of a separate police elimination database
- to email the Chair with questions that would stimulate discussion on the removal of loaded samples by 24 September

**Action: All NDNAD Ethics Group members**

- to ask the Regulator to circulate available information on the rules governing juveniles' and victims' samples on the NDNAD

**Action: Secretariat**

- to consider the form of response the NDNAD Ethics Group might wish to make to the PACE review

**Action: Madeleine Colvin**

### (iii) Commercialisation of the forensic market

19. It was noted that more service providers were coming into the forensic market and that some of these were based outside the UK. Standards needed to be maintained and any information stored had to be justified together with identity protection. This was the responsibility of the Custodian of the NDNAD, subject to new standards identified by the Regulator.

### (iv) Training in the use of crime scene kits

20. There was discussion about the level of training given to the police and others.

21. The NDNAD Ethics Group agreed:

- information should be sought about the training provided in the use of crime scene kits.

**Action: Secretariat**

### (v) Preparation of a DNA information sheet

22. There was discussion of the need to improve transparency and to assist the public understanding of DNA issues. The Chair made an offer to prepare a DNA information sheet which linked directly to a consent form.

23. The NDNAD Ethics Group agreed:

- a DNA information sheet and consent form(s) should be prepared.

**Action: Peter Hutton**

### (vi) International and information management issues

24. Differences in other countries' legal requirements were acknowledged and there was discussion about their ethical differences in handling DNA samples. There was interest in the statistical data available to support differences in sampling and convictions as well as outstanding European Court decisions. Questions were asked about how often the Information Commissioner and others reviewed the NDNAD and the standards used to store data.

25. The NDNAD Ethics Group agreed:

- to request details of the Information Commissioner and others reviews of the NDNAD and the standards used to store data.

**Action: Mike Prior**

(vii) Delivering better information to the public

26. There was discussion on how the public might be better informed about the NDNAD. It was acknowledged that the NDNAD Ethics Group's Annual Report was one vehicle. It was crucial that the NDNAD Ethics Group's independence was not compromised.

27. The NDNAD Ethics Group agreed:

- to review the role it could play in the light of outstanding European Court rulings
- to consider its information strategy at later meetings.

#### **Item 4: NDNAD Ethics Group meeting schedule: NDNADEG/030907/03**

28. Members were thanked for making time available for this meeting.

29. There was discussion about:

- difficulties in finding a suitable common date for meetings. It was noted that it was unlikely that all NDNAD Ethics Group members would be able to attend every meeting
- the benefits of giving advance notice of meetings with recurrent meeting dates.

30. The NDNAD Ethics Group:

- agreed it should aim to meet on the second Thursday of each quarter, starting with December. Therefore forthcoming meeting dates would be: 13 December 2007, 13 March 2008, 12 June 2008 and 11 September 2008. Keith Batten would check NDNAD Ethics Group members' availability.

**Action: Keith Batten**

## Item 5: The Appraisal system for NDNAD Ethics Group members: NDNADEG/030907/04

31. It was noted that an appraisal system for the members of non-departmental advisory bodies such as the NDNAD Ethics Group was a Cabinet Office requirement.

32. There was discussion about:

- the appraisal form which drew on the standard Cabinet Office template and provided a reporting structure with a transparent process
- whether other NDPB's had formally adopted the reporting structure. It was acknowledged that not all had, but it represented good practice and there was no case to be made against adoption of the appraisal system proposed.

33. The NDNAD Ethics Group:

- approved the recommendation in the paper, adopted the proposed reporting form and agreed that the Chair's report should be presented to the Regulator and countersigned by the Home Office Chief Scientific Adviser; members' reports should be presented through the Chair and countersigned by the Regulator.

## Item 6: Any other business

### NPIA Advisory Panel

34. It was noted that a NPIA Advisory Panel existed which planned to look at DNA issues.

35. The NDNAD Ethics Group:

- agreed further details of the Advisory Panel would be shared and members of the NDNAD Ethics Group might wish to contact them.

**Action: Wendy Coates & Keith Batten**

### Sharing comments outside formal meetings

36. The NDNAD Ethics Group acknowledged that circumstances might require decisions to be made and issues raised outside the formal quarterly meetings.

37. The NDNAD Ethics Group:

- agreed information could be shared and comments made by email where appropriate.

# NATIONAL DNA DATABASE ETHICS GROUP

Notes of the second meeting held on Thursday 13 December 2007 at the Civil Service Recreational Centre, Chadwick Street, London SW1

## Present:

Peter Hutton	NDNAD Ethics Group Chair
Wendy Coates	NDAND Ethics Group Member
Madeleine Colvin	NDAND Ethics Group Member
Michael Menlowe	NDAND Ethics Group Member
Sameer Sarker	NDAND Ethics Group Member
Sarah Thewlis	NDAND Ethics Group Member
Suzy Walton	NDAND Ethics Group Member
Clive Richards	NDAND Ethics Group Member
Jane Pearson	NDAND Ethics Group Member
Steve Bain	NDAND Ethics Group Member
Soheel Joosab	Home Office, FSRU (Secretariat)

## Apologies:

None

## Introductory comments

There are a number of additional sub-headings inserted into the text of these notes to signpost various topics for the ease of the reader. They are in blue italic script.

Abbreviations and terms used but not otherwise explained are as follows:

<b>ACPO</b>	Association of Chief Police Officers
<b>CJS</b>	Criminal Justice System
<b>Custodial sample</b>	A DNA sample obtained by the police from an arrested person. Such a person may or may not be subsequently charged, released or convicted.
<b>DNA profile</b>	The printout or electronic record obtained following DNA analysis which describes specific genetic markers related to the identification of an individual person

<b>DNA sample</b>	A stored sample of DNA from an individual or crime scene which can be analysed to produce a DNA profile
<b>ECtHR</b>	European Court of Human Rights
<b>PACE</b>	The Police and Criminal Evidence Act
<b>NDNAD</b>	National DNA Database
<b>NPIA</b>	National Policing Improvement Agency
<b>Volunteer sample</b>	A DNA sample obtained from a person who is not under arrest

Additional clarifications appear as footnotes when required.

When reading these notes, it will be seen that there is some overlap between Items 4 and 5. At the meeting they were considered in reverse order with some cross-over of content but are set out here so as to be in line with the agenda.

### Chair's opening remarks

PH welcomed MM, ST, CR & SB to their first meeting. SB was a newly co-opted member following a decision taken at the Ethics Group's first meeting (ref Item 1; para 5; NDNADEG 030907).

### Item 1: Note of the last meeting

1. The note of the last meeting which had previously been agreed electronically and placed on the Home Office website was formally approved as an accurate record.

### Item 2: Matters arising: NDNADEG/131207/05

2. PH noted that, following the last Ethics Group meeting, there remained an outstanding action to seek information on training provided to police, and others, on the use of crime scene kits.

**Action: Secretariat/WC/PH**

### Links with stakeholder organisations

3. The Group received an oral briefing from the Chair on the stakeholder organisations and individuals contacted and met with to date who had expressed views publicly on, or who had a legitimate interest in, the taking and retention of DNA profiles and samples. These were as follows:
  - Genewatch
  - Justice
  - Sir Alec Jefferies (the inventor of DNA profiling)
  - Police Leadership and Powers Unit; Home Office

- Liberty
- Nuffield Council on Bioethics
- Wellcome Trust
- Forensic Science Service
- Lord Justice Sedley (correspondence only)

The Chair reported that at all meetings the Ethics Group representatives had been well received and that the role and remit of the Ethics Group was welcomed. Following each meeting a letter was sent from the Chair to the stakeholder summarising issues discussed and confirming the main points the stakeholder would like to see addressed. Copies of these letters were in the papers circulated for the meeting. It was agreed that this *modus operandi* should be adopted as standard practice following a first meeting with stakeholders. There are further stakeholder meetings planned for the future. These include:

- The Human Genetics Commission
- The Information Commissioner
- The Conservative Party
- The Liberal Democrats
- The NPIA
- The Equality and Human Rights Commission
- The Royal Statistical Society

4. It was reassuring to the Ethics Group that the issues they themselves had already recognised (in previous discussions on 03/09/07 and e-mail exchanges) as requiring attention were very similar to those identified by stakeholders. These were as follows:

- The value of DNA analysis as an indispensable forensic tool was strongly supported: it was around the relevant law and use of the NDNAD and DNA samples that concerns were expressed.
- There was uniform concern over the holding of DNA profiles and samples obtained from volunteers and non-convicted persons on a 'criminal' database. This concern extended to the lifetime of data and sample retention for those who were minors at the time of sampling for whom consent had been obtained from a parent or legal guardian.
- At present the removal of data from the NDNA database and destruction of DNA samples is at the discretion of the local Chief Constable. This does not ensure a coherent policy and allows the possibility of inconsistency across the country.
- The statutory framework for the forensic use of DNA is opaque and would benefit from review and clarification.

- In the complete process of the taking and use of a DNA profile and sample, who should have access to the link between the personal details of the donor and the anonymised identification code used during analysis and storage?
- The process of consent for the taking of a volunteer sample needs review.
- Is it necessary to keep all custodial samples on the NDNAD for the lifetime of the convicted individual or could some crimes be seen as 'spent' after a period of time?
- Is it necessary to retain custodial samples on the NDNAD if the individual is neither charged nor convicted?
- There needs to be improved public information on what a forensic DNA sample is, what it is used for, and what information it can give.
- There need to be clear controls and governance arrangements for the use of DNA profiles and samples for research, but also, the potential value of research on the database should be appreciated.
- The limitations of, as well as the confidence in, DNA evidence need to be appreciated when used in court
- Was there a need to store a DNA sample as well as the DNA profile? This concern applied to volunteer and custodial samples from known persons but not to crime scene samples when retention of genetic material has obvious advantages.
- Why some social and ethnic groups were disproportionately represented on the NDNAD?
- What controls were there on the storage of DNA profiles and samples by commercial laboratories?

The Ethics Group agreed that all these were appropriate areas for consideration and that a programme of work needed to be set out to tackle them. Concepts such as proportionality and effectiveness were crucial to decision making and further research needs to be identified and commissioned to inform future discussions.

5. It was noted that a number of organisations had yet to reply to the letter of invitation to meet with them. It was agreed that these invitations should be repeated and where possible, combined with an approach from a member of the Ethics Group if they had special knowledge or links with the organisation.

**Action: PH and others**

6. The Group discussed whether any other stakeholders might usefully be added to the stakeholder table. It was agreed that the Council for the Registration of Forensic Practitioners should be included and contacted.

**Action: PH/SW**

## Ministry of Justice review on 'the use and sharing of personal information'

7. The Chair reported that following a visit to the Wellcome Trust, he had received a letter from the Director, Dr Mark Walport describing a review of '*The use and sharing of personal information*' that he and the Information Commissioner, Richard Thomas had been asked to carry out on behalf of the Ministry of Justice. They would shortly be commencing a consultation exercise and would welcome input from the Ethics Group and working with it in the future. It was agreed that we should respond positively to this suggestion. It was also noted that a meeting with the Information Commissioner was planned for early 2008.

## The Human Genetics Commission's 'Citizens' Inquiry'

8. It was reported that the Human Genetics Commission (HCG) had obtained funding to establish a "Citizens' Council" to review public views on the forensic use of DNA. This would survey approximately 200 people at group sessions in Birmingham and Glasgow and report in Spring 2008. The Ethics Group welcomed this initiative and commented that the combination of its own feedback from special interest groups (paras 3 – 6 above) together with that from this exercise would provide a good range of opinions. The Group concluded that it would be beneficial to collaborate with the HCG in relation to the Citizens' Council exercise and that it should be on the agenda at the planned stakeholder meeting with the HCG (see para 3 above).

**Action: PH**

## Item 3: Progress with the review of volunteer samples?<sup>9</sup> NDNADEG/131207/06

### On-going liaison with ACPO

9. The Group reviewed the work that ACPO had been progressing on the value and management of samples taken from volunteers. The Chair (PH) had first attended a meeting related to this in August 2007 (before the first meeting of the Ethics Group) and had been to others since. Two ACPO documents were considered: these were an account of a Volunteer DNA Process Workshop held jointly by ACPO and the Home Office and a report presented to the NDNA Strategy Board on the value of volunteer samples in November 2007. The group noted the content of both these documents and that the police had already had some discussions concerning the use of volunteer data and issues surrounding consent. In the former of the two documents a guidance DVD on Intelligence Mass Screening was referred to and the Group requested to have sight of a copy of this.

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<sup>9</sup> A 'volunteer sample' is a term that covers all samples taken from persons who have not been arrested. These are a heterogeneous group covering such situations as mass screening (which will eliminate many but may produce a suspect), voluntary entry onto the DNA database by former sex offenders and those who live in areas of endemic crime (for the purposes of them being able to achieve early elimination from suspicion when innocent), and samples taken from the presumed innocent to assist with the identification of contaminant DNA at crime scenes.

The Group also noted that the Chairman of the NDNAD Strategy Board had written to all Chief Constables in July 2007 indicating that they should anticipate possible changes to the volunteer sampling procedure and the loading of volunteer samples onto the DNAD.

**Action: Secretariat to obtain copies of Intelligence Mass Screening DVD**

**The purpose of the NDNAD and the legislation related to it**

10. For clarity, at the request of members of the group, the purpose of DNA storage on the NDNAD and the legislation surrounding sampling were reviewed.

**The purposes for which DNA profiles held on the NDNA database may be used.**

It was confirmed that the NDNAD was created in 1995. The database *per se* was not established under dedicated legislation but the Criminal Justice and Public Order Act 1994 (amending PACE 1984) gave powers to the police to take body samples and for the 'checking' against 'other samples or the information....contained in records held by or on behalf of the police or held in connection with or as a result of an investigation of an offence'. Subsequent 2001 legislation specifically restricted the use of DNA samples to 'purposes related to the prevention or detection of crime, the investigation of an offence or the conduct of a prosecution'. All other civilian uses are prohibited and this has been tested at law in the refusal to provide data for paternity testing<sup>10</sup>.

The Ethics Group were aware of suggestions (made in public by several individuals to prevent discrimination between individuals and ethnic groups), that it would be fairer to have the whole of the population on the database. It was also noted that expansion of the database to the whole population had been apparently encouraged by comments from some politicians.

A discussion followed considering the relevant factors which took into account issues of privacy, fairness, equality and ethnicity. Key points which emerged were:

- The reasons for taking and retaining DNA samples and profiles have been defined in legislation (as above) and this situation has not been modified. The spirit of the original law in 1994 was not that it should become a database containing the details of the whole population. Until the change in legislation in 2001, any DNA profile, sample or information derived from a custodial or volunteer forensic DNA sample had to be destroyed if there was no charge or conviction.
- Although there are arguments that can be made for the establishment of a national, civilian, non-criminal DNA database, they are very different from those used for the establishment of a crime-related database. Consequently, it is inappropriate and fraught with ethical and social problems to allow one to metamorphose into the other.
- Arguing that the database should be expanded to include all the

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<sup>10</sup> The only permitted exception to this (established in legislation as a modification within the Serious Organised Crime and Police Act 2005 following the aftermath of the South East Asian tsunami in 2004), is for the identification of deceased persons who happen to be on the NDNAD by chance.

population, (the majority of whom will never commit a crime), to prevent inequality is, on balance, unsustainable when issues of proportionality and personal privacy are taken into account.

## Aspects of legislation relating to the taking of a DNA sample

The Criminal Justice Act 2003 made provision for the police to take a DNA sample without consent from all persons arrested for a recordable offence<sup>11</sup> and detained at a police station. As far as could be ascertained by the Chair, there is no compulsion on the police to take such a sample, although custom and practice is such that this is now routine. Similarly, there is no compulsion on the police to load a custodial sample, once taken and processed, onto the NDNAD, but again, this is now routine. The DNA Expansion Programme (2000 – 2005) aimed at gathering the DNA profiles of all known 'active offenders' greatly increased the size of the NDNAD.

Operational police policy for the taking of DNA samples for offences which are non-recordable lies at the discretion of the Chief Constable of each force, and can only be taken with the consent of the suspected offender.

In the case of a volunteer DNA sample the individual can sign a consent for the sample to be used just for that investigation, or can consent for it to be loaded onto the NDNAD and retained indefinitely (where it would be subject to speculative searching). These two options are one below the other on the same piece of paper (a copy of which was supplied in the Group's meeting papers).

For the consent of the volunteer to be valid it is essential that the consequences of selecting which option to sign are made clear to them by the person taking the consent. If the volunteer does not give permission for retention and loading onto the NDNAD, the profile and the sample are held in the analysing laboratory on its own database for comparison to crime stains from that specific enquiry and destroyed when the case is closed.

If the volunteer profile is loaded onto the NDNAD and the sample retained, then it is very difficult for the volunteer, if they subsequently change their mind, to get the profile removed or the sample destroyed. This is because the law states that consent given in this circumstance is not capable of being withdrawn. The difficulty of removal also applies to those arrested but not charged or convicted. For the profile to be removed from the NDNAD and the sample destroyed, the individual has to apply to the Chief Constable who 'owns' all the DNA profiles and samples originating in his or her jurisdiction. The policy is that requests are only acceded to if there are 'exceptional circumstances'. These circumstances are not defined in law. If such a request is not granted, which is usually the case, there is no mechanism (either within or independent of the police force), except through formal legal challenge, to appeal against the decision.

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<sup>11</sup> Essentially a recordable offence is one for which the police are empowered to hold national records of offenders. Almost all criminal offences are now recordable including all imprisonable offences and, for example, most public order offences.

## Volunteer samples

11. Bearing in mind the considerations in the immediately preceding section, the ACPO reports referred to in para 9 (above) were considered with respect to volunteer samples. Importantly, the work presented to the DNA Strategy Board on volunteer samples in November 2007 illustrated that DNA matches between volunteer profiles and crime stains are satisfactorily achievable irrespective of whether the volunteer profiles are loaded from the analysing laboratory to the NDNAD. With the exception of sex offenders (who are sometimes sampled under the volunteer procedure), on the results to date, all of the matches would have been obtained without speculative searching of the NDNAD. There would be no loss to operational policing if, for the majority of crimes, volunteer samples were not loaded onto the NDNAD and were used only in relation to the investigation of the crime for which they were obtained.
12. Having weighed the pros and cons of the situation, and bearing in mind that:
  - Since September 2006, Section 45 of the Human Tissue Act 2004 has made it clear that testing an individual's DNA without their consent other than for specific 'excepted purposes' (which do not include volunteer sampling), is a criminal offence
  - Individuals have a right to privacy under human rights legislation,
  - The good will of the public needs to be fostered,
  - Operational policing would not be put at risk, and
  - There are cost saving from not storing DNA samples indefinitely,
  - The Ethics Group concluded that in the taking and use of volunteer DNA samples, the presumption should be
  - that these samples will be used only for the case under investigation,
  - that the profile will not be loaded onto the NDNAD, and
  - that the samples and all data derived from them will be destroyed when the case has ended.
13. The Group also considered the situation of those individuals who, as volunteers during an investigation (or at any other time) wished to have their DNA profile added to the NDNAD and their DNA samples stored indefinitely for their own reasons. Comparisons were drawn between DNA and other investigative and biometric markers such as fingerprints, blood group and iris scans where it was noted that it is quite unusual for individuals to request that their markers be taken and stored. It was concluded that although there may be certain circumstances in which the retention of an individual's profile on the NDNAD and retention of their DNA samples as a volunteer might be justified, there should be no automatic right that such a facility be offered to the individual.

14. For those rare circumstances in which loading onto the NDNAD and sample retention are deemed to be appropriate (e.g. sex offenders, a subject in an intelligence led screen), separate consent arrangements to those set out above in para 12 (above) and in Item 5 (below) should be used. These separate arrangements were not considered by the Ethics Group on this occasion.

**Action: Chair to write to ACPO and NDNAD Strategy Board about volunteer samples**

#### **Item 4: Information for the public: NDNADEG/131207/07**

##### Background to the Ethics Group's responsibilities

It had been agreed at the Ethic Group's previous meeting that the Group had a responsibility for making sure the public had access to good information on DNA profiling and its implications. Public information was also an important issue in the minds of the stakeholder groups surveyed to date (Item 2; para 4 above). Prior to the meeting, a trawl was undertaken of information available in the public domain on DNA and DNA profiling and some examples of this were circulated with the meeting papers. After discussion, the view of the Group was that the information which currently exists (some of which is very high quality), does not meet the specific needs of DNA profiling and the informed consent process i.e. there was no 'off the shelf' information base that could be readily adapted for the purposes of our work.

As agreed at the last meeting the Chair had developed some initial drafts of public information sheets but after a consideration of these before this meeting, it was felt that more discussion was needed on the content and target of such information before it could be recommended or approved for release. The view was put, and had considerable support, that although it was clearly a part of our responsibilities to make sure that such information was available, it was not necessarily our role to actually produce it.

For convenience during discussion, this item was divided into two sections:

- The necessary information base for those taking DNA samples from volunteers; and
- The information that should be made routinely available for those who provide samples, especially those who are volunteering a sample to assist the police.

##### **The necessary information base for those taking DNA samples from volunteers**

15. The Group considered the content of the current consent forms used in England and concluded that the narrative did not meet the criteria for informed consent. There was therefore an urgent need to prepare new consent forms and to ensure that there was additional high quality written or verbal information available when consent was taken. The point was made that people in the British population have a range of first languages and educational attainments and that in the provision of information these variables need to be accommodated. For consent to be valid, the information must be in a form and at a level that the

individual can understand. Although these criteria are mandatory for volunteers (otherwise it would be contrary to the requirements of the 2001 Criminal Justice and Police Act which permits the taking of samples and the Human Tissue Act 2004 and could breach privacy and equality rights under the Human Rights Act), the Group held the strong view that it would also be good practice to extend such standards of information to the taking of custodial samples.

16. Suggestions that taking DNA samples and using DNA kits was, on occasions, contracted out or delegated to those with little knowledge of the significance of the test raised significant concerns. The Group accepted that the actual technical exercise of taking the DNA sample was simple but it considered that the act of taking consent was much more demanding and impinged on requirements in both criminal and civil law. It recognised that the two events of consent and sampling might be conducted sequentially by separate individuals, but the Group was clear for the need of the person taking consent to be appropriately informed themselves and able to answer any reasonable questions put to them by the donor.
17. Although not to be considered a generalisation, the Group inferred that on some occasions, the person taking consent and the DNA sample might indeed demonstrate only a very limited knowledge of the implications of DNA profiling. Furthermore, there seemed little, or no, continuity across the 43 police forces on how training in this area of policing was being delivered. It was therefore agreed that the Ethics Group had a responsibility in the public interest to review this situation.
18. As a first step toward examining the current situation and the possibility of standardising guidance:
  - it was agreed that the Ethics Group should make an approach to Peter Neyroud, Chief Executive of the NPIA and,
  - if the findings indicated a need for action, the Ethics Group should offer to assist and share advice as appropriate on the drafting and delivery of such guidance.

If, after discussion, the NPIA wished to move in this direction, it was agreed that WC, ST, SB and the Chair would liaise with the NPIA on this area of work on behalf of the Group.

**Action: WC/ST/SB/PH**

## **The information that should be made routinely available for those who provide samples, especially those who are volunteering a sample to assist the police.**

19. There was a consensus within the Group that:

- the information easily available to the public and to volunteers (i.e. those providing DNA samples) was at present inadequate for the obtaining of 'informed consent', and
- that this needs to be corrected in parallel with establishing knowledge levels for those taking consent for a DNA sample.

It was agreed that the Ethics Group should approach the NPIA with a proposal that guidance/information for those providing a DNA sample should also be reviewed. If agreeable to the NPIA, the Ethics Group would wish to support this work in an advisory capacity. Their representatives would be WC, ST, SB and the Chair.

**Action: WC/ST/SB/PH**

## **Item 5: Consent and volunteer samples: NDNADEG/131207/08**

20. This item assumed the volunteers under consideration were competent adults: it was recognised that some volunteers will be minors or non-competent adults. These will be considered subsequently on a separate occasion.
21. Whilst it was noted that in law consent can be verbal and does not have to be written, it was considered that in the case of volunteer DNA sampling the situation was sufficiently complex that only written consent was appropriate
22. The Group reviewed the current volunteer DNA consent form for England & Wales (for information only, the Group also looked at the consent form used by Scotland). Prior to the meeting, documents published by the Department of Health relating to the requirements for taking informed consent for clinical procedures had been circulated to the Group for comparison purposes.
23. Following discussion, it was concluded that the process of consent provided by the current consent form with two consent options closely positioned (one for not loading onto the NDNAD and the other for loading and retention), no 'user-friendly' supporting information and a potential lack of consistency in the knowledge of the person taking the sample falls short of reliably meeting the requirements for consent to be valid.
24. There was considerable discussion about the nature of the relationship between a volunteer and the CJS. Essentially, a volunteer sample was a sample requested by the police to help them with their enquiries. As such, the individual donating the sample was contributing to the public good and, in so doing, was entitled to certain rights and privileges. Because at the time of DNA donation it was a voluntary act implying consensual testing, it was outside the 'excepted purposes' defined in Part 3, Section 45 of the Human Tissue Act 2004. As such, the donating individual had the right to determine the uses to which the sample would be put

and the Human Rights Act gave them certain rights of privacy.

25. On the basis of para 23, a satisfactory and equitable relationship between the volunteer and the CJS should include:
- An understanding that the *intent* in taking the volunteer sample is to help the police by providing information which will either eliminate the volunteer from suspicion or identify DNA which is an innocent contaminant at a crime scene<sup>12</sup>.
  - The provision of information on DNA profiling in a manner which the volunteer can readily understand, together with the volunteer having the opportunity to ask questions about the process.
  - Time for the volunteer to consider the implications of what is being requested
  - A clear understanding that the DNA profile and sample will be used only for the investigation for which it is provided and that at the end of the investigation the sample, profile and any other information derived from it will be destroyed.
  - An assurance that the profile will not be loaded onto the NDNAD or be subject to speculative searching.
  - The ability of the volunteer to withdraw the whole or part of their consent for the use of their DNA at any time.
  - The provision for the volunteer to provide a DNA profile without retention of the DNA sample.
  - Specific permission to use the sample as part of a research project.
26. The Ethics Group decided that it was within their remit to provide a revised consent form. This work would be taken forward on behalf of the Group by SW, MM, SS, and PH.

**Action: SW/MM/SS/PH**

### **Item 6: Identification and tracking of DNA samples: NDNADEG/131207/09**

26. The Chair informed that Group he had visited the Forensic Science Service in Birmingham and seen how DNA samples are processed and analysed. Both he and the FSS were concerned about the confidentiality of sample handling. At present, the system transfers DNA samples to analysing laboratories with both an anonymous bar code and a paper record which carries personal identifying information.

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<sup>12</sup> If a volunteer subsequently becomes a suspect and is arrested, then they would automatically lose their privileges of volunteer status and fall under the legislation in the CJS.

27. Following a brief discussion, the Ethics Group was unanimous in concluding that both volunteers and those required under the CJS to provide a DNA sample had a right to confidentiality and privacy with respect to the details of the sample provided and the information derived from it. Knowledge of the link between the personal details of the person and the anonymous bar code on the sample and the derived profile must comply with a strict 'need to know' principle. A useful analogy was drawn between this situation and that of medical records being subject to Caldicott Guardianship and legislation through the PIAG system<sup>13</sup>.
28. Given the present government policy to 'out-source' aspects of the forensic services to bodies outside the jurisdiction of the CJS, the Ethics Group concluded that the methods of anonymising and tracking DNA samples needed to be reviewed with considerable urgency. There was a need for complete clarity of process and well defined oversight or guardianship of sample identification. The Ethics Group considered that this might possibly lie with the NDNAD Custodian, dependent on the Custodians scope and remit following the review of forensic regulation currently under way.

**Action: PH to discuss with NDNAD Custodian**

29. The Chair reported that following recent breaches in information security at national level in other areas, a letter had been received from the Chairman of the NDNAD Strategy Board concerning data integrity and security in relation to DNA records. It was agreed that the Ethics Group should collaborate with the NDNAD Strategy Board and the Information Commissioner in ensuring the maximum accuracy, reliability and security of personal DNA information.

**Action: PH to discuss with Chair of NDNA Database Strategy Board**

**Item 7: Response to the PACE review: NDNADEG/131207/10**

31. At the previous meeting of the Ethics Group, MC was asked to evaluate the current status of the PACE review and to produce a report for the Ethics Group. Her report was circulated prior to the present meeting.

Also circulated was a report prepared for the Ethics Group by the Home Office on the comparative legislative position within the EU for the collection, storage and retention of DNA. There was considerable variability between countries in the use and handling of DNA and the UK is substantially different from them all in the higher proportion of its population on a national database.

32. After opening the item and commenting on her paper, MC reported that she and the Chair had recently met with the Home Office Police Leadership and Powers Unit (PLPU). The meeting was requested by the Ethics Group, through the Chair, to discuss mutual aspects of remit, how the Ethics Group might work effectively in relationship to the PLPU, and in particular on how the Group might actively participate in the PACE review. It was an opportunity to share with the PLPU problems which had been identified by the Ethics Group.

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<sup>13</sup> The Patient Information Advisory Group (PIAG) was established to provide advice on issues of national significance involving the use of patient information and to oversee arrangements created under Section 60 of the Health and Social Care Act 2001.

It was found that in several areas there was agreement on issues that needed attention and both sides shared some mutual concerns. The PLPU would welcome future collaboration with the Ethics Group and its input into the PACE review. The possibility of a member of the Ethics Group being on the Home Office PACE review committee was mentioned. The current timeline remains for the final PACE review consultation to be published in Spring 2008. **Action: MC/PH to follow up**

33. The areas of concern identified that the Ethics Group would like to feed into the PACE review are:

- There is no proper statutory footing for, and oversight of, the operation of the NDNAD
- The discretion of Chief Constables to define the 'exceptional circumstances' under which DNA profiles and samples may be deleted and destroyed is potentially inconsistent and discriminatory and contrary to an individual's privacy rights. Currently, there is potential for regional variation in decision-making in respect of a national service which has no governing statutory regulations. In particular, this results in it being unclear when lawfully permitted intrusions on a person's privacy are allowed.
- There is no right of appeal or any independent appeal mechanism for an individual to challenge the decision of a Chief Constable without formal use of the judicial system. This deficiency is one of the key grounds in the case of *S and Marper* before the ECtHR<sup>14</sup>. The Group noted that the outcome of the *S and Marper* case is likely to have significant effects in the UK whichever way the judgement goes.
- The Group thought it important that it had a view on the holding of unconvicted persons' data on the NDNAD (and DNA samples) by the time of in-putting to the PACE review.
- As identified in other parts of these notes, the present management of volunteer samples and consent needs attention.
- The possibility of international data sharing and its regulation by international treaty needed careful consideration.

**Action: MC/PH to follow up**

36. During discussions on this item, a member of the Ethics Group referred to the existence of a national ACPO Good Practice Manual related to the taking, analysis, storage and retrieval of DNA profiles and samples. It was felt that copies of this document should be obtained for the Group members for their information.

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<sup>14</sup> The Group had had sight of the former NDNAD Custodian's submission to the House of Lords in the *S and Marper* case but the appendices to the submission were missing. These were an essential part of some of the arguments developed in the submission and it was decided to try to obtain them. **Action: PH**

## **Item 8: Discretion of Chief Constables and already loaded samples**

37. Although a separate agenda item, much of the consideration of this item has been covered earlier and is set out in the above paragraphs.
38. Additional discussions centred around those persons who had been arrested but not subsequently charged or convicted and there was examination of the ramifications for an individual within this category. An individual may, for example, not realise that their DNA profile remains on the NDNAD and there is a second DNA sample in storage or that the retention and possible use of that information may infringe their rights to privacy. The justification to retain such DNA profiles and samples on an indefinite basis may not stand up to scrutiny of the public interest. Again there was disquiet expressed at the deprivation of an innocent individual's rights to determine issues of their own privacy in the presence of a Chief Constable's discretionary powers. It was decided that we should return to a reconsideration of this category of individuals at a subsequent meeting.

**Action: Secretariat**

39. It was agreed that research was needed to determine whether there are any statistics on the correlation between those arrested but not charged or found not guilty and who then subsequently go on to offend.

**Action: Secretariat**

40. There was also a further discussion concerning the status of DNA profiles on the NDNAD and retained samples from previous volunteers. It was concluded that if the earlier recommendations regarding the prospective taking of volunteer samples were implemented (Item 5 above), then fairness and equity would dictate that all existing volunteer samples and profiles on the NDNAD should be reviewed. Various approaches were considered and a provisional consensus emerged that it would be impractical to give individuals the 'option' of removal or retention. Since retention cannot be justified on operational grounds (para 11 above), the only non-discriminatory and practical response would be to delete them all. This issue needs further attention will be returned to at a subsequent meeting of the Ethics Group.

## **Item 9: Forward planning: development of work plan & allocation of jobs: NDNADEG/131207/12**

41. Following an action from the inaugural Ethics Group meeting to develop a work plan for presentation to the responsible Minister, the Chair led a discussion on an outline programme of work for the next three months (to end of March 2008) and the following year thereon.
42. Following discussion, the Ethics Group agreed the following work plan.

**a. Workstreams for completion by end March 2008**

1. To produce a paper summarising key issues raised through meetings with stakeholders
2. To produce recommendations on the secure identification and tracking of samples (possibly drawing on the Caldicott Principles as an analogy)
3. To produce a draft revision of the research application forms used to request research on DNA samples held on the NDNAD (see Item 10: AOB)
4. To have fully engaged with the NPIA and agreed a way forward on the revision of the consent process, consent forms and the improved provision of information on DNA for volunteer samples.

**b. Workstreams (provisional) for completion for year April 2008 – March 2009**

5. To contribute to the PACE review (as described above in para 33).
6. To make recommendations on the status and retention of existing volunteer data on the NDNA database
7. To review and make recommendations on the value to the CJS of holding DNA profiles and samples on those who had been arrested but not subsequently charged or convicted
8. To examine and make recommendations on the statutory framework within which operation of DNA sampling, analysis, storage, retention and oversight occurs.
9. To compare the situation in the UK with that in other countries
10. To develop links with the Royal Statistical Society with an aim to delivering better guidance on the interpretation of statistical data
11. To commission any work necessary to support the above items
43. To meet the commitment of producing and delivering the work plan to the Minister, there is an expectation that the Ethics Group will 'sign off' the finalised work plan before end of March 2008.

**Item 10: Any other business and date of next meeting.**

44. A point was raised that requests for access to samples, or profiles, on the NDNAD for research and development purposes are made by completion of a pro-forma and channelled through the NDNAD Custodian. There was such a request currently pending. It was noted that there had been disquiet concerning the research governance arrangements voiced by a number of stakeholders.

Following a discussion it was concluded that there were some legitimate concerns regarding the substance and format of the pro-forma and process. Accordingly, it was felt that an approach should be made to the NDNAD Custodian with a proposal that he and the Ethics Group together revise the pro-forma and its associated documentation to bring them more closely into line with the procedures used in medical research trials. If, following such an approach, the Custodian was agreeable, the members representing the Ethics Group would be JP, CR, SB and PH.

**Action: JP/CR/SB/PH**

#### **45. Dates of next meetings**

Due to a clash of dates with the Ethics Group and the NDNAD Strategy Board, the following dates are a revision of those previously intended.

13 <sup>th</sup> March 2008,	13:30-17:00
5 June 2008,	11:00-16:00
18 September 2008,	11:00-16:00

# NATIONAL DNA DATABASE ETHICS GROUP

**Notes of the third meeting held on Thursday 13 March 2008 at the Home Office, 2 Marsham Street, London, SW1P 4DF**

## Present:

Peter Hutton	NDNAD Ethics Group Chair
Julia Ayetey	NDAND Ethics Group Member
Steve Bain	NDAND Ethics Group Member
Derrick Campbell	NDAND Ethics Group Member
Wendy Coates	NDAND Ethics Group Member
Madeleine Colvin	NDAND Ethics Group Member
Sameer Sarkar	NDAND Ethics Group Member
Sarah Thewlis	NDAND Ethics Group Member
Suzy Walton	NDAND Ethics Group Member
Clive Richards	NDAND Ethics Group Member
Jane Pearson	NDAND Ethics Group Member
Keith Batten	Home Office, FSRU (Secretariat)

## Apologies:

Michael Menlowe	NDAND Ethics Group Member
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## Introduction

Peter Hutton welcomed those present to the third meeting of the National DNA Database Ethics Group and Julia Ayetey and Derrick Campbell to their first meeting.

## Item 1: Note of the last meeting

The note of the second meeting held on 13 December 2007 was formally agreed subject to the following amendments:

- Change spelling of *Jefferies* to *Jeffreys*
- Change *Police Leadership and Powers Unit* to *Police Powers and Protection Unit*

## Item 2: Matters arising

### The Forensic Science Regulator

It was reported that Adrian Cory (the interim Forensic Science Regulator) had been replaced by Andy Rennison. The Ethics Group recorded formal thanks to Adrian Cory for his hard work in the creation of the Ethics Group.

### Tony Lake

It was reported that responsibility for the ACPO forensic science portfolio had been split and passed from Tony Lake to Gary Pugh and Chris Sims. The Ethics Group recorded formal thanks to Tony Lake for his work and support in the creation of the Ethics Group.

### Meetings with stakeholders

The Ethics Group noted the meetings held and planned which had been attached as annex A to the meeting agenda. These were as follows:

### Meetings attended/presentations given etc

- 3<sup>rd</sup> December 2007: Presentation on Ethics; Police Strategic Command Course
- 20<sup>th</sup> December 2007: Sir John Sulston at the HGC (with Steve Bain)
- 8<sup>th</sup> January 2008: NDNA Screening Conference, Solihull
- 8<sup>th</sup> January 2008: Information Commissioner; (with Sarah Cunningham Burley)
- 15<sup>th</sup> January 2008: Rt Hon David Davis MP, Damien Green MP, and their staff (with Wendy Coates and Madeleine Colvin)
- 23<sup>rd</sup> January 2008: Presentation on ethics Group at Forensic Science Regulator Stakeholder Conference
- 24<sup>th</sup> January 2008: Interviews for new Ethics Group Members
- 30<sup>th</sup> January 2008: Evidence to House of Lords Select Committee on the Constitution concerning 'the surveillance society'.
- 25<sup>th</sup> February 2008: Presentation to the Citizen's Inquiry on the NDNAD
- Letter to the Times 26<sup>th</sup> February 2008
- 7<sup>th</sup> March 2008: Mike Prior, the NDNA Custodian (with Clive Richards)

### Future meetings

- 19<sup>th</sup> March 2008: Commission for Equality and Human Rights; London
- 20<sup>th</sup> March 2008: The Forensic Regulator (Andrew Rennison); London
- 25<sup>th</sup> March 2008: Action on rights for Children

- 3rd April 2008: NPIA (Peter Neyroud); London
- 3<sup>rd</sup> April ACPO (Tony Lake), London
- 7<sup>th</sup> April ACPO police ethics portfolio meeting
- 25<sup>th</sup> April DNA Boost meeting

### **Meeting dates awaited**

- Crown Prosecution Service
- Council for the Regulation of Forensic Practitioners
- Royal Statistical Society
- Liberal Democrats Home Affairs Office (no reply, one follow up letter)
- Serious Organised Crime Agency

### **Chairman's letter to the Times**

The Ethics Group noted the content of the letter the Chairman had sent to and been published in the Times on 26<sup>th</sup> February 2008 and which had been attached as annex B to the meeting agenda.

### **Crime scenes kits**

The Ethics Group noted that a meeting was to be held with the NPIA where these would be reviewed.

### **A Practitioners Guide to Intelligence Led Mass DNA Screening**

The Ethics Group took receipt of the joint Home Office / NPIA CD on mass screening. Keith Batten reminded the Ethics Group that the document was restricted and its security must be maintained.

### **The use and sharing of personal information**

The Ethics Group noted that Peter Hutton had written to the Wellcome Trust who were working on this with the Ministry of Justice and would chase a response.

**Action: Peter Hutton**

### **Recommendations on taking and storing volunteer samples & information for people being sampled**

The Ethics Group noted that:

- (i) meetings with the NPIA and ACPO were planned for the first week in April 2008 to inform them of our recommendations to date and to discuss future issues
- (ii) Steve Bain, Wendy Coates & Sarah Thewlis had met with Ariela Ferber at the NPIA earlier and reviewed the written advice NPIA had prepared

for those providing samples. The NPIA appeared to be working to a short deadline and had sent their drafted written advice to print before receiving comments from the Ethics Group. The NPIA would be contacted to confirm a revised second version would be prepared, possibly in other languages.

**Action: Steve Bain, Wendy Coates, Sarah Thewlis, Peter Hutton**

- (iii) Peter Hutton would raise the NPIA consultation process with Peter Neyroud.

**Action: Peter Hutton**

### Consent forms for volunteers samples

The Ethics Group noted that this appeared as substantive agenda item 3.

### Research application forms

The Ethics Group noted that this appeared as substantive agenda item 4.

### Security of data and identifying codes

Peter Hutton shared a handout which included a flow chart showing how samples were derived, managed and loaded onto the National DNA Database. The Ethics Group re-confirmed its view that there should be clear regulations stating who, or what organisation, should have knowledge of the link between the personal details of the person donating the sample and the bar code used during testing and storage. This applied to both volunteer and CJS samples.

The Ethics Group noted:

- (i) the exchange of correspondence between the Information Commissioner and Dr Mike Prior dated 21 January 2008 & Peter Hutton and the Information Commissioner dated 18 January 2008
- (ii) Peter Hutton would contact Dr Mike Prior to clarify some points raised in the exchange of this correspondence and to plan a way forward on the issue of confidentiality and data retention.

**Action: Peter Hutton**

### The PACE Review

The Ethics Group noted that the discussion on DNA in the CJS within the PACE review was delayed pending determination of a case before the European Court but reiterated its view that a statutory framework for the database and the storage of samples was essential to meet human rights issues and to preserve public confidence.

### HGC Citizens' Inquiry

The Ethics Group noted that the Citizens' Inquiry was not expected to report until after 13 May 2008.

## Useful information factsheet

The Ethics Group agreed that a “key statistics” briefing should be prepared and shared. Keith Batten said he was aware that the NPIA provided some data and would be presented to the next Ethics Group meeting. This would also be discussed at the meeting with the NPIA in April.

**Action: Secretariat**

## House of Lords Report: “Young Black People and the CJS”

The Ethics Group agreed that the House of Lords Report should be shared.

**Action: Secretariat & Wendy Coates**

## The use of DNA evidence alone in Northern Ireland

The Ethics Group noted:

- (i) reports that cases were presented to court in Northern Ireland with only DNA evidence to support them
- (ii) there were subtle differences in the criminal justice systems in use in England & Wales; Scotland; and Northern Ireland
- (iii) comments should be sought from Karen Squibb-Williams at the Crown Prosecution Service.

**Action: Peter Hutton**

## Forthcoming meeting of the House of Commons Select Committee on the Surveillance Society

The Ethics Group noted that Peter Neyroud was to give evidence to the Select Committee.

## Briefing for Home Office Ministers

The Ethics Group noted that at a recent broadcast interview, Tony McNulty MP appeared unsighted on the work of the Ethics Group. Keith Batten said that while he was not aware of the interview, Tony McNulty was not the Home Office Minister with responsibility for the Ethics Group. He may have been interviewed unexpectedly and before briefing could be prepared.

## Dates for future National DNA Database Strategy Board meetings

The Ethics Group noted that the last scheduled meeting of the Strategy Board had been cancelled. Future meeting dates would be obtained and shared.

**Action: Peter Hutton**

### Item 3: Volunteer consent form for DNA sampling and accompanying information: NDADE/130308/13

The Ethics Group noted the work undertaken and the draft form prepared. The Group thanked SW, SS, and MM for their efforts in producing the draft.

There was discussion about:

- (i) how the police responded where an individual declined to give a voluntary sample
- (ii) the use of volunteer samples for research purposes and satisfying the conditions of consent and data protection
- (iii) ownership of the sample
- (iv) notification of removal of a sample from the database
- (v) where the sample and the profile would be held.

Amendments to the draft consent form were suggested to:

- remove reference to being “arrested”
- show that consent could be withdrawn at any time
- include a date and the same style for the two signature spaces
- include additional questions on “Where will this DNA sample and the information it provides be kept” & “How will I know when this sample has been destroyed”
- remove “criminal” from the question title
- re-order the questions.

The Ethics Group agreed:

- That the consent form was intended for a volunteer sample only: if a person became a suspect and was arrested, a second procedure should be undertaken. There should be no conversion of the existing volunteer consent: to mix volunteer and CJS samples was seen as potentially confusing to the consent process.
- members of the Ethics Group should share with the Home Office examples of police behaviour towards volunteers which could give rise to concern

**Action: all Ethics Group members**

- an amended version of the draft consent form should be shared and agreed in correspondence before being submitted to the NPIA.

**Action: Peter Hutton<sup>15</sup>**

#### Item 4: Draft DNA research ethics information form: NDNADEG/130308/14

The Ethics Group noted the work undertaken and the draft form prepared. The group thanked JP, SB and CR for their efforts in producing the draft forms.

There was discussion about:

- (i) what form of research should be permissible
- (ii) whether storage or intellectual property rights issues existed
- (iii) how research could be quality assured and how the risks of 'considering each application on its own merit' could be mitigated.

Amendments to the draft research ethics information form were suggested to:

- ask whether any other bodies or organisations were being approached to consider this research
- include a pre-amble which set guidelines on what types of research were covered by the form
- move the question "what are the main ethical issues with the research" to the top of the form
- confirm whether the sample or the data it produced would be sent overseas.
- What the results would be used for and where would they be reported

The Ethics Group agreed:

- a steer should be sought from the National DNA Database Strategy Board on the sample storage or intellectual property rights issues and included in the amended version of the draft research form which would be shared in correspondence

**Action: Peter Hutton**

- a process should be identified by which the Ethics Group would handle research applications

**Action: Peter Hutton**

- a letter should be prepared to introduce the research form when it was sent to the NDNAD Strategy Board

**Action: Peter Hutton**

- The final content of the Research Ethics Information Form should be agreed in correspondence by the Ethics group

**Action: Peter Hutton<sup>16</sup>**

## Item 5: Proposals for a way of classifying data: NDNADEG/130308/15

The Ethics Group took receipt of the paper prepared by the chair for discussion which sought to classify personal data into 4 categories. After discussion, the feeling of the group was that this

- Over-simplified a complex area
- That at present there was no sufficient need to develop the proposal further
- That a clarification of some aspects of the Data Protection Act and Article 8 of the European Convention on Human Rights should be prepared.

**Action: Madeleine Colvin**

## Item 6: Future direction and activities of the group

Peter Hutton invited the Ethics Group to consider how it should develop and how information should be shared.

There was discussion about:

- (i) whether to accept the request from Andy Rennison, the Forensic Science Regulator, to meet with the Ethics Group at its next meeting
- (ii) how best to ensure the Ethics Group was seen and perceived to be independent of the Home Office
- (iii) whether a web address without reference to the Home Office website should be sought
- (iv) how to handle enquiries from the public and press.

Keith Batten reminded the Ethics Group that Home Office Ministers were expecting a business plan and annual report from the Ethics Group. He acknowledged that the first business plan and annual report would be unusual as the Ethics Group had only recently formed. However, Ministers would be likely to expect the report to dovetail with the financial year end (5 April 2008) and to include narrative setting out the Ethics Group's purpose, objectives, delivered (actual) outputs, stakeholder views & forward plan. He said the report could suggest quarterly meetings with the Minister at which Peter Hutton could report on progress and secure recognition for the work of the Ethics Group.

The Ethics Group agreed:

- Andy Rennison should be invited to attend the fourth meeting of the Ethics Group
- an annual report and business plan should be prepared, agreed with members and submitted to Ministers as soon as possible
- the methods of publicising actions, liaising with the media and developing a web site should be kept under review.

**Action: Peter Hutton**

## **Item 7: Any other business & date of next meeting**

It was agreed that a date should be set as soon as possible for the new members of the Group and those who had not already done so to attend an induction session

**Action:Secretariat**

### **Next meeting**

The fourth meeting of the National DNA Database Ethics Group would take place at 11am on Thursday 5 June at the Home Office, 2 Marsham Street, London, SW1P 4DF.

## ANNEX 1

**Please note that this and the following page are intended to be on the same piece of paper**

### Consent form for voluntary DNA sampling

You have been asked to voluntarily provide a sample of your DNA. You are under no obligation to do so but doing so may assist the police in their enquiries. It may also help to eliminate you from the investigation.

If you agree to provide a DNA sample, it will be used only in connection with the current case. Your consent for its use can be withdrawn at any time.

Your sample and all information associated with it will be destroyed when the case is closed.

The information from your sample will not be entered into the national DNA database.

Please read the information on the back of this form before signing it. If you want more information, the officer taking consent for your sample will provide it.

### I am voluntarily supplying a sample of my DNA.

Your signature \_\_\_\_\_

Print name \_\_\_\_\_

Date \_\_\_\_\_

### I confirm that the procedure of sampling has been explained to the volunteer.

Signature \_\_\_\_\_

Print name \_\_\_\_\_

Date \_\_\_\_\_

# DNA AND YOUR RIGHTS AS A VOLUNTEER

## What is DNA?

DNA is a chemical substance in your body. It is a form of protein found in hair and body fluids, such as blood, saliva and semen. Each person's DNA is unique. Traces of people's DNA can be found in many places including at crime scenes.

## Can I refuse to give a sample?

Yes.

## What use is DNA in a police investigation?

Since each person's DNA is unique, traces of DNA can be used to identify individuals. It's bit like a fingerprint. It gives no information on genetic diseases.

## Where will this information be kept?

Your volunteer samples and the information associated with them are kept in the laboratory that analysed them.

## How will I know when it has been destroyed?

You will receive a written confirmation.

## How do I withdraw my consent for its use?

By contacting the police authority that took the sample.

## How is my DNA sample taken?

A sample is usually taken by brushing the inside of your mouth with a specially shaped cotton swab. This is not uncomfortable. Hair samples may be taken as an alternative to mouth swabs.

## What is the National DNA Database (NDNAD)?

- The National DNA Database is an electronic library of DNA profiles that have been collected by the police from individuals and from crime scenes.
- It is a tool used to solve crimes.
- Using the NDNAD may also eliminate the innocent.

If you have access to the Internet and you would like more information you can go to [www.npia.police.uk/en/8934.htm](http://www.npia.police.uk/en/8934.htm)

Version April 2008

Ends.

## ANNEX 2

### DNA Research Ethics Information Form

This form should be completed for all applications to conduct research on DNA samples and/or information held on the National DNA database.

Please complete the form using terminology which can be understood by lay members of the review team.

**Title of proposed research**

Investigator details:

**Name of Researcher:**

**Address of researcher:**

**Email:**

**Telephone number:**

**Employment details:**

Details of Proposed Research

Please identify the ethical issues which may be associated with this study and wherever possible indicate how it is intended to address these ethical issues.

Has this study been submitted to any other regulatory or government body for approval to conduct the research? If so please give details.

**Proposed start date of research**

**Primary purpose of the research:**

- Publicly funded study
- Home Office requested research  
Educational qualification
- Establishing a database/data storage facility
- Other, *give details:*

**What type of data is being requested?**

Full anonymised

Link anonymised

Fully identifiable

**What is the principal research question/objective?**

*(Must be in language comprehensible to a lay person.)*

**What are the secondary research questions/objectives?**

*(If applicable, must be in language comprehensible to a lay person)*

**What is the scientific justification for the research? What is the background? Why is this an area of importance?**

*(Must be in language comprehensible to a lay person)*

**Give a full summary of the purpose, design and methodology of the planned research**

*(This section must be completed in language comprehensible to the lay person)*

**How has the scientific quality of the research been assessed?**

- Independent external review
- Review within a company
- Review within a multi-centre research group
- Review within the Chief Investigator's institution or host organisation
- Review within the research team
- Review by educational supervisor
- Other

### Governance and Indemnity Arrangements

**Is the researcher governed by any research governance arrangements?**

**If so please specify the organisation providing research governance support.**

**Does the researcher have any indemnity arrangements to cover this research?**

**If so please provide details.**

**How is it intended the results of the study will be reported and disseminated?**

*(Tick as appropriate)*

- Peer reviewed scientific journals
- Internal report
- Conference presentation
- Other publication
- Submission to regulatory authorities
- Access to raw data and right to publish freely by all investigators in study or by Independent Steering Committee on behalf of all investigators
- Presentation to participants or relevant community groups
- Other/none

## Confidentiality and Storage of Data

**Where will research data be stored? (i.e. desktop computer, laptop computer, written records)**

**What measures have been put in place to ensure confidentiality of personal data?**

**Give details of whether any encryption or other anonymisation procedures have been used and at what stage:**

**Where will the analysis of the data from the study take place and by whom will it be undertaken?**

**Will the data be transferred out of the UK at any time during this study? If so what measures are in place to insure the security and confidentiality of the data?**

**Who will have control of and act as the custodian for the data generated by the study?**

**Who will have access to research participants' or potential research participants' dna records or other personal information?**

**For how long will data from the study be stored?**

## Statistics and Data Analysis

**How have the statistical aspects of the research been reviewed?**

**What is the primary outcome measure for the study?**

**What are the secondary outcome measures?**

**How many samples are being requested?**

**How will these samples be selected?**

**Randomly**

**Sequentially**

**Based on demographics if so please specify which demographics**

**How was the number of samples decided upon?**

*If a formal sample size calculation was used, indicate how this was done, giving sufficient information to justify and reproduce the calculation.*

**Describe the methods of analysis (statistical or other appropriate methods, e.g. for qualitative research) by which the data will be evaluated to meet the study objectives**

## Funding of the research and conflicts of interest

**Who is funding this research?**

**Will individual *researchers* receive any personal payment over and above normal salary for undertaking this research?**

**Will the host organisation or the researcher's department(s) or institution(s) receive any payment or benefits in excess of the costs of undertaking the research?**

**Does the Chief Investigator or any other investigator/collaborator have any direct personal involvement (e.g. financial, share-holding, personal relationship etc.) in the organisations sponsoring or funding the research that may give rise to a possible conflict of interest?**

**Other issues:**

**Other key investigators/collaborators**