The Ethox Centre welcomes this opportunity to comment on the work being carried out by the Nuffield Council on Bioethics on the forensic use of bioinformation. We hope that these comments will be helpful.

1. The identification of ethical issues
The consultation paper addresses the ethical issues arising in the forensic use of bioinformation. Within this context the inclusion of a section (Section 4.3) entitled ‘Ethical issues’ does not really work. This section, which lists four questions under the heading ‘Ethical issues’, seems odd to us, as it suggests that the other topics and questions covered in the paper are not concerned with ethics, or do not involve very significant ethical issues. It is our view that many other areas covered in the paper have serious ethical components and implications, and that these risk being obscured or missed because they are not explicitly identified as such. Some examples of significant ethical issues implicated elsewhere in the paper include:

- The question of what would constitute the appropriate management of the NDNAD, especially ethical oversight of access to it and uses made of it.
- The integration, sharing and/or cross-referencing of different types of databases, and potential implications (both for individuals and groups) of the uses and users of databases changing or expanding over time.
- Policies around the taking and retention of bioinformation, including consent.
- Database access policies, including the potential consequences for individuals of different users having access for various (including currently unforeseeable) purposes.

2. The interpretation of bioinformation and accuracy concerns
Whilst not being scientists, we have concerns about the ways in which the accuracy of DNA testing within the NDNAD will be ensured, given the very serious harms associated with false positives in forensic settings. It is in our view essential, for ethical reasons, that testing techniques should be reviewed regularly, with independent oversight, so as to be as rigorous as possible. Possible options might include doing a full genome sequence analysis once an apparent match is made, and conducting a number of different tests to verify apparent matches. We are particularly concerned that accuracy within the database has the potential to decrease over time as the NDNAD expands, because more individuals who are related may be included.

The danger of false positives is compounded by the disproportionate representation of certain groups within the NDNAD. We find this especially ethically troubling. If there is even a small risk of false positives, this carries huge implications with regard to equity for overrepresented groups. Moreover, it carries the clear potential to reinforce the negative stereotyping of young ethnic minority males as being criminals. The disproportionate presence of certain groups within the database means that they are still more likely than at present to be the subject of investigation.
This response was submitted to the consultation held by the Nuffield Council on Bioethics on the Forensic use of bioinformation: ethical issues between November 2006 and January 2007. The views expressed are solely those of the respondent(s) and not those of the Council.

These concerns lend support to the paper’s call for greater lay input and public debate. However, we also believe that there is a need for caution here. Given the presence of stereotyping of such groups within the public at large, it is essential that the kind of public debate and lay input obtained be informed by ethical principles, including transparency, inclusiveness and justice, so that negative stereotypes are not simply reinforced.

3. Consent and retention of bioinformation and DNA samples

It is our view that, in the cases of individuals who are either not suspects, not charged, are acquitted or are volunteers, consent should be a prerequisite for continued retention of bioinformation, and that this consent should be revocable. In medicine, biosamples (and any information derived from them) generally may be retained and used only with consent, which may be withdrawn freely. From an ethical perspective, we see no reason why the same standards should not apply equally in the forensic context. We believe, moreover, that the current guidance—whereby individuals such as those who have been wrongfully arrested and who wish to remove their DNA samples and fingerprints from police databases must demonstrate why their cases are exceptional—should be reversed. It is our strong view that it should be for the police to show why retention is justified, rather than the other way around.

4. Uses and secondary uses of bioinformation

A fundamental area of ethical concern for us arises out of the potential future uses and secondary uses of bioinformation (including biosamples) held in police databases. To some extent, inevitably, the potential harms from secondary use, including research use, remain unknown, as we cannot know how technology will develop in the future or what may become possible. Neither, of course, is it possible to predict future social or political arrangements. This uncertainty is particularly concerning in relation to the NDNAD, given both that the police effectively retain individuals’ whole genomes by keeping their samples, and that there is an unequal distribution of different social groups within the database. This suggests a need for caution. Again, issues around access, use and secondary use of biosamples (and associated data) have been addressed carefully in the biomedical research field. Many controls have been developed there, including ethical oversight. We recommend that the same level of controls and oversight should apply in the forensic context.

A further difficulty that emerges from the paper is the apparently blurry distinction between ‘research’ and ongoing investigation of individual cases. For example, what the paper terms ‘forensic research’—e.g., on-going research into serial crimes—might, perhaps, more accurately be classed as ‘continuing investigation into individual cases’.

Clarifying the distinction between this kind of investigation and research unrelated to the solving of a particular crime is important. For, we believe, much greater, independent review and scrutiny is needed of all research uses that are not simply ongoing individual case investigations. This includes, in our view, research conducted to improve testing or detection techniques. Research on the development of a test to establish hair colour from DNA, for example, may have enormous implications. Therefore, such research should be open to independent, prior ethical scrutiny and approval—as in the medical research field—as well as ongoing ethical monitoring.
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5. Ethical review and oversight
As noted immediately above, the controls, safeguards and oversight mechanisms currently in place for police databases, especially the NDNAD, are not, in our view, adequate. It is our view that robust scrutiny by an independent, publicly accountable, ethical monitoring body, equipped with directly enforceable powers, is needed. Whilst custodianship of the NDNAD has been kept in the public sector, this is not in our view sufficient to allay the concerns discussed above. It is not straightforwardly the case that the UK public has good reason to trust the State to protect individuals’ privacy and other interests in maintaining control over the use and dissemination of bioinformation. Accordingly, we recommend an independent and transparent review framework.

In addition to these broader ethical issues, there is also the potential for ethical issues to arise in the use of the database, and in the use of genetic testing, in the day-to-day practice of solving crimes. There is, for example, the danger that individuals may discover, through inappropriate disclosure, otherwise unknown sensitive information about themselves as a consequence of forensic DNA analysis. Such information may include revelations about their paternity, their status as having been adopted, or their genetic disease susceptibility or carrier status. Such issues have been addressed within biomedicine through the development of good practice and guidelines. We believe that the same standards and protections should apply in the forensic context. Overall indeed, we see no reason why ethical standards and protections for individual rights and interests should be lower in the forensic setting, with regard to ethical control and consent procedures, than those that are accepted within medicine. Within the medical science and biomedical research field there are well thought out guidelines, kept under regular review, and established (and improving) procedures for independent ethical review. By contrast, the forensic science area seems to lag far behind. We see no good reason why this should continue to be the case.

6. Further issues
In addition to the question of whether forensic databases ever should be made available for non-criminal use, which is discussed in the consultation paper, there is a further and related question of police access to and use of non-forensic databases, for forensic purposes. This raises the question of whether non-forensic databases—including large, searchable genetic databases such as UK Biobank and other epidemiological resources, or other clinical sample collections—should be vulnerable to external access and use (such as by police, other security services, or national or international public agencies) and, if so, under what conditions; or whether instead they should be protected by law from such external access.

In turn, the possibility of universally including all citizens in a national database at birth raises the question of whether such a database should be limited to forensic use or, instead, should be established to serve multiple purposes—for example, both forensic and public health benefits in the public interest. Each of these questions warrants further careful discussion and public debate.

The Ethox Centre, January 2007.