

The Forensic Use of DNA and the National DNA Database

Wellcome Trust response

November 2008

1. The Wellcome Trust is the largest charity in the UK. It funds innovative biomedical research, in the UK and internationally, spending around £600 million each year to support the brightest scientists with the best ideas. The Wellcome Trust supports public debate about biomedical research and its impact on health and wellbeing.
2. The Wellcome Trust is pleased to respond to the HGC's consultation on the important topic of the forensic use of DNA and the National DNA Database (NDNAD). Given the Trust's interests as a research funder, this brief response focuses on issues related to research and governance (as raised by questions 7, 8 and 9 of the consultation document).
3. The Trust is aware, however, of both the complex ethical issues that surround the use of DNA databases and the need for public engagement on this controversial topic. The Trust has funded grants in this field via our Biomedical Ethics programme and our various Public Engagement funding schemes, which included co-funding the Citizen's Inquiry. Other current funded activities include:
 - "Inside DNA: a genomic revolution" – a unique 5-year touring exhibition that encourages visitors to explore the issues underlying genomics research. Feedback from this exhibition is being shared with the HGC;
 - "The National DNA Database on Trial: Avoiding the Usual Suspects" – participants in this mock trial to be held in November 2008, will consist of people aged 16-19 whose details are already on the NDNAD. Findings will be disseminated widely and presented to both the HGC and Welsh Assembly;
 - "Forensic DNA Databasing: A European perspective" - a biomedical ethics grant to Professor Robin Williams and Dr Paul Johnson to explore the growth of national DNA databases across European states; the implications of increased trans-national forensic DNA data sharing across the EU and the major legal, social and ethical issues arising from the emerging global trends in the forensic use of DNA; and
 - "Governing Genetic Databases" - a biomedical ethics grant being undertaken by Professor Michael Parker and Dr Jane Kaye from the Ethox Centre, University of Oxford and Dr Andrew Smart of Bath Spa University.

Comments in response to consultation questions

Governance of the NDNAD (Q7)

4. The Trust recognises that the question of which individuals are included on the NDNAD is an enormously sensitive issue. There will also be increasing potential to infer phenotypic information from DNA samples, and the extent to which this should be incorporated into the scope of the NDNAD is likewise highly contentious. These are questions on which a plurality of views exist – both within the Wellcome Trust and more broadly – and on which an ongoing public debate will be vital.

5. In light of these concerns, it is essential that strong governance arrangements are established for the NDNAD to consider its development, management and use over time. We agree that an appropriately constituted and resourced independent body should be established to oversee the resource. This should be transparent; have a clear remit and mandate; and have appropriate powers to fulfil its responsibilities (which are not compromised by those of other relevant bodies).
6. The UK Biobank Ethics and Governance Council (EGC) provides one model of an independent oversight body in the context of medical research. Although the requirements of UK Biobank will differ significantly from those of the NDNAD, the way in which the EGC aims to promote public trust and maintain independence are relevant – in particular:
 - the use of an open appointments process for the chair, vice chairs and all members in keeping with the Nolan Principles of Public Life;
 - selection of members from a variety of disciplines so that it benefits from a range of experience and perspectives, with members acting in their own personal capacity and not representing their affiliated organisations or other interests;
 - maintaining an appropriate relationship with UK Biobank (i.e. sufficiently arms-length to maintain independence but sufficiently engaged to fulfil its remit);
 - making its work public by a variety of routes - including published minutes of meetings, full accounts of its deliberations, and public engagement activities to inform publics about its role and to gauge attitudes about UK Biobank.

Linking the NDNAD with research databases (Q8)

7. The Trust considers that it is imperative that there is a complete and absolute separation between the information collected for forensic purposes and held in the NDNAD and information collected for research purposes in the context of biobanks and other research databases.
8. We would therefore strongly oppose any move to link the NDNAD with research databases and would welcome measures to prevent this type of systematic linking. The use of research samples and data for purposes beyond that for which consent was gained from research participants would breach the second Data Protection Principle (which prohibits reuse of information in any manner that is incompatible with the original purpose) and could irrevocably damage public confidence in research.
9. In short, the creation of such linkages would:
 - compromise the confidential nature of the relationship between research participant and researcher and lead to a breach of trust;
 - undermine the reputation of the relevant databases and research organisations, which could lead people to choose not to participate in research studies;
 - compromise the privacy of citizens who contributed to these various endeavours to improve the health of others;
 - create a particular ethical problem in respect of children included in medical and research databases and biobanks, who have not been able to consider the implications of being included, and of being 'linked' to a forensic database;
 - cause logistical problems and associated costs for researchers with respect to recruitment and retention of research subjects – i.e. have to seek reconsent.

Research in behavioural genetics (Q8)

10. The potential secondary use of genetic information collected within the NDNAD for behavioural genetic research is a complex issue. We would note that any such research should only take place with the express consent of the donor (the preferred model) or with completely anonymised (broad phenotype only) samples/data with Research Ethics Committee approval. The secondary use of data is an issue that the biomedical research field has considered in great detail, and it will be important to build on the lessons learned if this activity is to be considered within the NDNAD.
11. We would also note that:
 - the NDNAD was not established as a research database and the manner in which the samples/data has been collected might not always make it scientifically useful;
 - the NDNAD is also not a “criminal” database in the sense that it is not solely populated by those who have been convicted of a crime. Therefore, anyone interested in criminal behavioural research would need to identify the particular type of offenders they are interested in and seek their consent.

Linking datasets (Q9)

12. The question and example in relation to “correlating” information with other database is unclear. We are not sure what the difference is between “linking” in question 8 and “correlating” in question 9. That said, we believe our response in relation to question 8 – linking with other databases and research in behavioural genetics (paragraphs 7-11) - is relevant here.