

Identity and DNA

Prof. Simon Rogerson

**Originally published as ETHicol in the IMIS Journal Volume 18
No 5 (October 2008)**

Scientific advances continue to amaze. No more so that the work in DNA and genetics. The question must always be asked of how a scientific advance will help humankind and the world at large. Recently the increasing use of DNA and genetic information to establish identity has come under public scrutiny. The Human Genetics Commission has undertaken a study of citizens' attitude towards the UK National DNA Database. This database is the largest of its kind in the world holding data of over one million people including 100,000 children. Genetic material is taken from all people arrested whether they are then charged and convicted. This data remains of the database forever. Baroness Joan Walmsley has concerns about this database. She points out that, " The Government is collecting more and more information about us, but seems utterly incapable of keeping it safe.... One of the fundamental tenets of British justice is innocent until proven guilty. By refusing to destroy samples from those who are never charged with a crime or who are later acquitted completely blurs that principle."

Such concerns are shared by others. The HGC study found the majority of participants concluded that:

- the retention period for profiles on the database should be proportionate to the seriousness of the crime for which the person to whom they relate was convicted
- the ethnic group of a person from whom a DNA sample was taken should not be recorded as this could contribute to discrimination
- samples should be destroyed and profiles removed from the NDNAD when a suspect is not proceeded against or an accused person is not convicted at the conclusion of criminal proceedings

Baroness Walmsley continued "We also call for the removal of all DNA samples of children under the age of 16, except those who have been convicted of a violent or sexual offence. Placing children on the NDNAD may actually increase their propensity to commit further crime, making the retention of their samples entirely counter-productive." This sentiment is echoed in the HGC report.

The collection of ethnic profiling data has raised much concern. Christian Today (6 September 2008) reported on research by the human rights campaign group Black Mental Health UK which has shown public opinion to be very strongly against the

practice of adding the DNA and ethnicity data to the National DNA database of mental health patients who come into contact with the police but have not committed a crime. Health experts have warned this is criminalising one of society's most vulnerable groups. The Rev Paul Grey was reported as saying, "Why are people on the database if they haven't committed any crime? People needing mental health care are vulnerable and when people are vulnerable it is important to protect them. Part of the freedoms and civil liberties we have in this country is that we are able to keep what belong to us, and there is nothing more personal than our DNA."

Questions of access and anonymity surround DNA data as well. The Contra Costa Times (28 Aug 2008) reported privacy concerns over a database of so-called anonymised DNA profiles of 60,000 volunteering patients had led to the National Institutes of Health in the USA blocking public access to this database. "A new type of DNA analysis could confirm the identity of an individual in a pool of similarly masked data if that person's genetic profile was already known. Such a confirmation could reveal the patient's participation in a study about a specific medical condition, experts said, and deny the patient their presumed confidentiality". It is clear that advances in genetic science are leaving policy and legislation in its wake. Fred Bieber, a medical geneticist at Harvard Medical School was reported as saying, "The lesson is that with enough genetic information, it's becoming easier to identify individuals even though their identities are presumed to be made anonymous."

These issues surrounding DNA databases are about trust. It is about the relationship of citizens with government and its agencies. How much confidence do citizens have in their government to collect, store and use DNA and genetic information in a way which is acceptable to us? Such trust is not simply based upon an intellectual assessment but an emotionally experienced sense of security and assurance. Both are equally important. Our measure of trust is based upon what we think of the other party's benevolence, honesty, sincerity, openness, and caring. To date those responsible for the policy and operation regarding databases such as the National DNA database do not seem to be fairing well.

Please send your views on ethical and social responsibility issues and cases of ethical dilemmas to:

Professor Simon Rogerson
Director
Centre for Computing and Social Responsibility
Faculty of Computing Sciences and Engineering
De Montfort University
The Gateway

Leicester

LE1 9BH

Tel: (+44) 116 257 7475

Fax: (+44) 116 207 8159

Email: <srog@dmu.ac.uk>

Website: (<http://www.ccsr.cse.dmu.ac.uk/>)