

Whose DNA Is It Anyway? European Court, Junk DNA, and the Problem With Prediction

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In this article, we discuss the implications of a recent European Court of Human Rights (ECHR) decision about the use of retained DNA profiles in criminal cases. Met with polar but equal passion from both the privacy lobby and law enforcement, this case has opened concerns regarding ethics in the nascent science of DNA profiling. Although the technology is touted as the most exciting breakthrough since fingerprinting in crime solving, there are questions regarding its use. The case decided by the ECHR intensified the debate on privacy, state control of information, and the public's right to be safe. New proposals in response, however, raise more questions than they sought to answer, ranging from unfettered data mining to the pitfalls in risk prediction.

J Am Acad Psychiatry Law 38:247–50, 2010

On May 21, 2008, President George W. Bush signed into law¹ the Genetic Information Nondiscrimination Act (GINA), which prohibits U.S. insurance companies and employers from discriminating on the basis of information derived from genetic tests. The British Insurance industry has also voluntarily declared a moratorium until 2014² on basing coverage decisions on information about noncoding DNA sequences. However, no similar decisions have been reached in the United Kingdom about the use of genetic information for criminal investigation pur-

poses. A recent judgment by the European Court of Human Rights³ proclaiming disproportionate violation of the right to privacy and family life (Article 8 of the ECHR) by DNA profile retention in criminal justice databanks raises questions about the interface between health care information and criminal justice.

Two individuals (S., a minor, and Michael Marper) were charged with offenses that resulted in fingerprint, cellular, and DNA samples being taken (lawfully) as part of a criminal investigation.³ The charges against both were resolved without conviction, and both S. and Mr. Marper sought to have their identifying information (including DNA profile) permanently removed from any police database. They were unsuccessful in the lower courts and so took their case to the European Court in Strasbourg. The case was heard publicly on February 27, 2008, and the unanimous decision of 17 judges was delivered on December 4, 2008.³

The court found that the “blanket and indiscriminate nature” (Ref. 3, ¶ 119) of the power of retention of the fingerprints, cellular samples, and DNA profiles of persons suspected but not convicted of offenses, failed to strike a fair balance between competing public and private interests and ruled that the

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United Kingdom had “overstepped any acceptable margin of appreciation” (Ref. 3, ¶ 125) in this regard. These are very strong words for a usually soft-spoken court, and the decision is nonappealable.

DNA Profiling and Retention of Samples

The technique of DNA profiling was pioneered in the United Kingdom, and it was the first nation to establish a criminal justice DNA databank. Jointly with the United States, the United Kingdom has the largest DNA databank (some 5 million profiles). Britain, however, has the largest forensic DNA database in the world in proportion to the size of its population (8%). Despite the passion that usually accompanies any “big brother” issue, the U.K. medical community has so far been unusually quiet about the retention of DNA profiles (or samples) on criminal justice databases. This silence is somewhat puzzling, given that DNA is a component of human tissue (as described by the Human Tissue Act 2004), and under U.K. law, express consent must be obtained before it can be used for any medical purpose. The Act was passed following some well-publicized scandals about organ and tissue retention in the United Kingdom, and it has had a highly negative impact on medical research.^{4,5}

Before this ruling, in 2004, the United Kingdom’s then highest court (the House of Lords) unanimously took the view that DNA retention is a proportionate and legitimate state interference in private life. Only Baroness Hale of Richmond disagreed slightly,⁶ stating that she “[could] not agree with the view. . . that the retention and storage of fingerprints, DNA profiles and samples is not an interference with the appellants’ rights under article 8(1).” She nevertheless agreed that collection of “as many samples as possible. . . benefit[s] and enhances the aims of accurate and efficient law enforcement” (Ref. 6, ¶ 78). In the meantime, the debate about universal DNA databanks or a massively expanded one continues.

The U.K. Human Genetics Commission⁷ first publicized ethics-related concerns about DNA testing in 2002, primarily in relation to employment discrimination but also in relation to the right to individual privacy. More recently, the Nuffield Council for Bioethics⁸ also drew attention to the ethics-related tensions about privacy and social benefits arising from DNA research. However, they did not address the complexities of the use of DNA in the criminal context. Specifically, there has been no ar-

ticulation of what should be done with legally seized, but abandoned DNA; i.e., police have the power to collect DNA samples off anything on the street without first arresting and bringing the suspect in to a police station. That means they can collect your DNA without your knowledge from any bodily samples one leaves behind in public. At present, the police are allowed to take abandoned DNA material and keep it for future crime detection purposes. In a very recent publication,⁹ the Human Genetics Commission articulated the public’s concerns about the holding and use of genetic information by the state for legitimate crime-solving purposes.

New Developments in Genetic Identification Markers

Over the seven years that the *S. and Marper v. The United Kingdom*³ case took to come to its conclusion, major advances in knowledge have been made about DNA and genetics that have implications for the privacy of health care information and for crime detection. The decoding of the human genome started in 2003, and the last sequence of the last chromosome was decoded in May 2006. It is now possible to analyze DNA from a miniscule amount of cellular samples, and the more recent advancement in the analysis of mitochondrial DNA (mtDNA) means that DNA from samples like hair, teeth, and bones can now be tested. As mtDNA comes only from the mother (fathers only contribute to nuclear DNA), comparing the mtDNA profile of crime scene DNA with the profile of a potential suspect’s maternal relative can be an important technique in crime solving. The use of this technique could also give rise to concerns about familial searching and profiling.

The applicants in *S. and Marper* were primarily concerned about the implications of having their identifying data left on a police database for the police to access in the future. They were right to be concerned: continuing technological advances make future use of DNA for ever-more-detailed profiling highly likely. Take for example, the use of short tandem repeats (STRs) in the analysis of forensic DNA or DNA used for databanking. STRs are used to evaluate different loci within nuclear DNA, and the variation in the STR region is used to distinguish one DNA profile from another. Some STRs are referred to as junk DNA because they are thought to have no biological function and cannot be used for individual identification.

However, recently there has been evidence that some junk DNA may be a biological marker for particular traits. This finding is significant because it implies that forensic STRs could be useful for predicting physical traits, with implications for both criminal and personal profiling. Both the United States and the United Kingdom utilize STRs (13 STR loci) to match samples from their database CODIS (Combined DNA Index System). A recent example is the refinement of technology that has identified a noncoding STR as a marker for red hair, theoretically allowing for enhanced criminal profiling.¹⁰ That there has been no use of forensic STR in genetic profiling of suspected criminals to date does not mean that it could not (or would not) be used. Research from Europe¹¹ suggests that STRs may be useful in following or tracking genetically acquired disease. Whether the medical community will ultimately choose to use STRs to screen for specific diseases is uncertain; but it is perhaps disingenuous to suggest that forensically obtained STRs do not contain information about medical conditions or ethnicity—precisely the scenario privacy advocates are worried about.

It has been argued that a DNA profile “is very much like a social security number—though it is longer and is assigned by chance, not by the federal government” (Ref. 12, p 58) and, as such, should have no particular social significance. Many scholars^{13–18} believe that the debate ought not to be about whether genetic information has predictive value, but about how far, as a society, we are prepared to invest in discovering the predictive value and the purposes to which this predictive information is put.

Ancestral DNA, Ethnicity, and Function Creep

A recent off-the-cuff comment by an immigration official in the United Kingdom raised a controversy,¹⁹ as it stoked fears that many already had that DNA might be used in an attempt to determine an immigrant’s country of origin. Individual DNA variants known as single nucleotide polymorphisms (SNPs) in mitochondrial DNA on the Y chromosome and elsewhere in the genome have made it possible to determine the geographic origin of the donor to within about 100 km in some cases. Although the notion was berated immediately by the scientists in the journal *Nature*,²⁰ theoretically, it would not be

an impossible task to pinpoint the origin so closely in the near future at the rate technology is advancing.

What is sometimes called function creep is essentially the incremental (although not necessarily exponential) enlargement of scope or the addition of new functions where there is a benefit to be gained by using the technology or process in new ways. The concept of function creep makes some people nervous, especially when there is a general lack of transparency. The concerns about DNA phenotyping and the complex problems in its reliability as a crime-fighting tool have just been mentioned. Similarly, the relatively new discipline of behavioral genetics (and its spinoff criminogenics) where genetic variations and behavior are correlated is the subject of much public speculation. While in reality both geneticists and psychiatrists agree that concerns about the application of behavioral genetics research to criminality are presently misplaced, speculation and fear are fueled by both the lay and the professional media.

Rapid progress in research on junk DNA may lead to its widespread collection in the belief that it has some predictive value. The temptation would then be to draw inferences from the data that have significant social consequences in terms of the use of health care information for financial advantage, the public good, and criminal investigation and detection. For example, faith in the racial impartiality of the criminal justice system on both sides of the Atlantic has dwindled, but the existing confidence could be further undermined if behavioral patterns, for example, are linked with other phenotypic components such as skin or hair color.

Conclusions

Those sitting on the fence in this debate do not know which poses a greater threat to liberty, the ideology of genetic determinism or the technology of DNA databanking. Kaye¹³ perhaps puts it best: “[A] warrant requirement will not make much difference to a society that, under the sway of a naive and discredited theory of genetic determinism, is willing to lock people away on the basis of their genes.” Society will have to think long and hard about the competing values of security and personal freedom and the dangers of allowing technological advances to determine social policy. The ECHR ruling may be just the beginning of the debate.

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