

“Are people’s DNA sequences their business and nobody else’s?”

The completion of the Human Genome Project in 2003 heralded a new era in the study of human biology. While DNA sequencing is an exciting technology, it also raises a lot of ethical issues. DNA is uniquely specific to one person and one small sample provides huge amounts of highly personal information. So how much privacy should we be entitled to regarding our DNA?

My immediate answer was that of course every person should be entitled to full privacy. It is their DNA and therefore their inherent right to decide if and to whom they divulge the information. However this issue is more complex. One very topical issue is that of DNA databases. It is an issue which we should all consider because presently the government is in the process of establishing a DNA database in Ireland. The legislation has yet to be put through and I think it is very important that we have a national debate on this matter due to the significant number of ethical issues.

The first question is - whose DNA profiles should be on this database? Perhaps only people who commit serious criminal offences should be profiled? However, this raises the question about what is a serious offence? The England and Wales DNA database which is proportionately the largest in the world provides a good example of function creep. At first only serious criminals were recorded, now anyone who commits a recordable offence may be profiled. An increasing number of innocent people are present on the database including 24,000 innocent children. Discrimination also plays a role. In the UK 40% of black men are on the database in stark contrast to 6% of white men. To reduce discrimination some suggest that a national database containing everyone’s DNA profile would reduce inequality and abolish any stigma. I admit that the thought of my DNA on a national database makes me uncomfortable. Yes, if you have nothing to hide, you have nothing to fear, but you also feel like a suspect rather than a democratic citizen. The right to liberty, the right to privacy and the right to be presumed innocent until proven guilty are all civil rights which we have fought for and now thankfully enjoy in today’s democratic society. I have to ask, “Are we giving up these basic rights in the attempt to fight crime and is it worth it?” Personally I think it is a waste of resources to profile the entire population. England and Wales spent 300 million on their database in the last 5 years alone! The criminal population is small and I agree with the proposed Criminal Justice bill that only those who have committed a crime which earns a one year prison sentence or longer should be profiled. After committing a crime it is only just, then, that the right to your DNA is lost, in the interest of the common good.

Interestingly, your actual DNA sample does not necessarily need to be stored in the database. The part of DNA used for identification does not contain genes which indicate predisposition to diseases and other sensitive information. The DNA profile is a unique but meaningless sequence which can only identify the person as being male or female. The issue which raises contention is the storage of DNA samples. The reason given for this is that technology is still progressing and the system used now may become outdated so samples are retained. This varies from country to country. It is illegal everywhere to use samples for anything other than forensic DNA identification but who would know if they were, when many are stored in third-party laboratories? Function creep in the UK has meant that some companies are now allowed to carry out research on samples and the idea of merging ID cards and DNA profiles is being considered. I feel that the retaining of DNA samples is an absolute violation of the privacy of a person's body. DNA for research should only be attained through informed consent.

The value of DNA databases is undeniable and I think we do need one. We can demonstrate this with the case of a woman from the West of Ireland who was sexually assaulted. The Gardaí eliminated all suspects and her attacker was only convicted after the DNA sample matched a sample on the UK database. The crime would not have been solved otherwise. It is important also that we do not accept that DNA evidence is infallible. It must be collected, sampled and stored correctly. It is vital that juries convict only when it is supported by motive, eyewitnesses, CCTV evidence etc. The value of a DNA database will depend solely on its integrity. Therefore, the right safeguards are essential to ensure its reliability. Strict legislation to prevent function creep and to prohibit the storage of samples is crucial.

So with whom else might we have to share our DNA sequences? Well, the most frightening, is that building societies, employers and insurance providers may insist on you disclosing your DNA sequences. This has not happened yet but it would be reassuring to have legislation put in place to deem this illegal. These organisations would argue that in accordance with the principle of 'Utmost Good Faith' we must disclose all facts and our genes are statistics like all others which are analysed. A fair point, but I think genes are uniquely personal and to live in a democracy means to live in a country where the authorities are not allowed to intrude into every aspect of our lives. We need to protect and preserve our freedom and autonomy. Genetic discrimination is a term I hope we will never have to use.

I believe our DNA sequences are our business. It is time to draw the line at the intrusion of the authorities into what is confidential. A DNA criminal database is acceptable but we need to establish boundaries because DNA technology is ever advancing and who knows what the future will hold?

By: Lisa Duffy

Reference: The Irish Council for Bioethics