

Are people's DNA sequences their business and nobody else's?

By Anna Tomalczyk

DNA is passed from parents to their offspring, giving each person their individual and truly unique genetic code. In 1953, James Watson and Francis Crick discovered the meaning of life, sharing the structure of DNA with the world. We now know that our genetic code is a sequence of nitrogenous bases, which give us our specific characteristics and traits through protein synthesis. Variations within the human population are clearly visible and are caused by mutations - changes in the sequence of the nitrogenous bases. Scientists have already made enormous discoveries using Watson and Crick's DNA model, and are on the cutting edge of so much more.

From microscopic samples of blood, skin or hair; genetic profiling allows scientists to look at the genetic code of individuals. Parents can find out if their child is predisposed to a genetic disorder through genetic screening. They can also see if their child has genetic markers for breast cancer or Alzheimer's. Crime scene DNA samples and sequences, genetic screening and paternity screening involve the production of DNA databases. My curiosity about these DNA databases is the confidentiality of information, their misuse and their abuse.

In the words of Margaret Cho, *"Privacy and security are those things you give up when you show the world what makes you extraordinary"*. A DNA database that would contain information about our genetic codes could redefine the meaning of privacy if used improperly. Moral and ethical issues arise as to who should and should not have access to these databases. People with genetic disorders or with markers for genetic diseases could lose their chance of being employed or insured because of genetic discrimination. Would health insurance companies, life insurance companies and employers be biased against such people? This preconceived idea and lack of education about genetics is perhaps the main reason people could feel deprived of privacy and security and disagree with the idea of the existence of DNA databases. But how far can this go?

The positive aspects of new personal information storage (ie: DNA databases) could be very beneficial. There are limitless uses of DNA referencing. It could be used to help in cases of missing persons or for child abduction investigations, as even an alteration of the appearance of a person could not contradict a matching genetic profile. In the tragic instance of natural disaster or acts of terrorism as in the World Trade Centre Attack in 2001, identification would have been made easier with the availability of a DNA database. Medically DNA databases could make huge contributions to ongoing gene therapy and genetic engineering research.

Although people's DNA sequences are their business, anyone has the right to share their genetic information. With genetic profiling now possible, people who would decide to carry out

the test would gain knowledge about possible genetic disorders that could develop in their bodies or that they could pass on to the next generation. For instance, instead of carrying out amniocentesis and increasing the risk of miscarriage or escalating the controversy about pregnancy termination, women who would know that they are capable of passing on a genetic disorder could perhaps find alternatives to pregnancy, or contribute to research that would help develop methods or even cures for 'faulty' DNA like gene therapy for instance. With new information and a full human gene map available to researchers, assigning disorders that can affect us to their corresponding genes would be much easier. Theoretically, once the genes that are responsible for various diseases are found, gene therapy should be able to cure the diseases, even permanently. Those with genetic markers for other disease could through lifestyle choices improve their chances of survival.

Genetics help scientists understand how genes work and create many useful products for our benefits. For instance one of the first genetically engineered medicines was insulin, which many people with diabetes depend on today. Then came the human growth hormones that replaced compounds previously extracted from corpses, the vaccine for hepatitis B and other drugs and medicines.

So why keep DNA sequences a secret? My DNA is mine, it makes me truly unique, the person I am today, the person I will be in the future. I will pass some of my DNA to my children. I would like to see people being encouraged to contribute to medical research focusing on genetic therapy, hoping that one day it can save lives. I also hope that one day prejudice and bias will vanish. I agree with the idea of DNA databases, and I would hate to see them misused. I would despise living in an intolerant and unjust world portrayed by the movie "GATTACA". I wonder did Watson and Crick envisage such a world when they discovered DNA? Where would Watson stand on this argument today?

Finally, I would like you to consider Albert Einstein, Issac Newton, John Nash, Stephen Hawking, Alexander Graham Bell, Leonardo Da Vinci. A few of the extraordinary minds that lived, made major contributions to science and suffered from genetic disorders. Had they been alive today and if their parents had altered their DNA sequences in fear of discrimination or bigotry, would we be where we are today?