

**ADDRESS BY HON D. GOKHOO,
MINISTER OF INDUSTRY, SCIENCE
AND RESEARCH**

**AWARENESS WORKSHOP
ON
LEGAL ASPECTS OF THE USE OF
HUMAN DNA**

MONDAY 08 JUNE 2009

AT 09 00 HRS

**R. BURRENCHOBAY LECTURE THEATRE,
UNIVERSITY OF MAURITIUS, REDUIT**

Hon J. Valayden, Attorney General, Minister of Justice and Human Rights

Hon R. Jeetah, Minister of Health and Quality of Life

Mr H. Whittall, Director, Nuffield Council on Bioethics

Prof S. Jugessur, Pro-Chancellor and Chairman of Council, UoM and Chairman, MRC

Prof S.D. Rughooputh, Acting Vice Chancellor, UoM

Goodmorning.

I am delighted and honoured to be invited today to address you on the occasion – Awareness Workshop on Legal aspects of the Use of Human DNA.

While emerging economies in the developing world, such as India, China and Brazil, are investing heavily in innovative science and technology (S&T), the situation in sub-Saharan Africa has so far been different. The proportion of gross domestic product (GDP) spent on research and development is low (around 0.3% for Mauritius). However, in terms of understanding the importance of S&T and innovation for economic and social development, the situation is changing and Mauritius, as a member of the African

Union, has endorsed the call to achieve the target of spending 1% of its GDP on innovative S&T.¹

The use of human DNA spans across a wide range of potential applications, including those related to forensics and to health/genomics. For countries that have already embarked on major genomics initiatives, the first stages of establishing research institutes and conducting specialised research are completed. These countries are now considering how they will move from their early-phase investment towards health-oriented applications that can generate economic and social benefits. For other countries that are yet to make the initial significant investment, the questions are: what are the potential entry points, what are the challenges and opportunities, and importantly in the context of this workshop, what are the potential ramifications beyond the expected socio-economic benefits?

This workshop therefore comes at an opportune moment, when we are about to introduce a national Science, Technology and Innovation Policy.² The workshop will allow us to examine various facets of the use of human DNA and to better understand the

¹ Juma C and Serageldin, I. *Freedom to Innovate: Biotechnology in Africa's Development. Report of the High-Level African Panel on Modern Biotechnology.* African Ministerial Council on Science and Technology, 2007.

² *Science, Technology and Innovation Policy* (prepared by the Mauritius Research Council for the Ministry of Industry, Science and Research; May 2009).

interdependent nature of efforts, especially concerning the legal, ethical and regulatory aspects, that are now necessary for innovative S&T.

Background and policy context

The discovery of DNA has triggered enormous changes and advancement in a number of fields, but its use has also raised concern regarding the level of surveillance and privacy in many countries. Many citizens are concerned about the potential for misuse of personal information, particularly information that is stored in a DNA database. It is therefore important that various stakeholders, including policymakers, the judiciary, police and members of the public, are well-informed.

Generally, DNA surveillance can be broken down into two different categories. In the first, DNA is used in a way that allows for a link between two known people to be detected. Police and investigators will examine DNA profiles from people – all stored in a national database – with DNA found at crime scenes. In the second approach, police or investigators will look for a match between a person's DNA and any evidence gathered from a crime.

The UK holds the title of having the world's largest DNA database. This is due, in part, to the profiling that occurs from people arrested for even minor offences that do not result in jail sentences.

DNA and civil rights

While the discovery of DNA has provided incredible progress for mankind in areas such as medicine, forensics and paternity testing, it has also raised widespread controversy regarding human civil rights.

Policy makers cite that anything which improves efficiency in the police force is worthy of consideration, and therefore arguments for expanding DNA databases still continue to grow. Conversely, global attention to the databases has been raised and the use of profiling and its potential effect on civil rights has similarly increased. There have been suggestions that when newborns have their DNA taken for screening of possible genetic disorders, their DNA should then be placed in the DNA database. This point of view outlines the premise that civil rights are secondary to protecting the public. Others argue that we should be able to accomplish both goals - safeguarding the public and using DNA

where appropriate to track crime, but not applying the database to each citizen.

The use of DNA in prosecuting criminals years or decades after the crime was committed, or the use of DNA to exonerate an innocent person, have also brought forth the importance of databases. The idea that the inconvenience or infringement on civil rights that results from the profiling is irrelevant to public safety is a challenging debate. Still, one also has to consider that DNA could be misused or misinterpreted as well. A person who was at the crime scene but is innocent of the crime could be incorrectly pursued as a perpetrator of the crime.

In the context of Mauritius, an important issue is whether legislation will be introduced to make it compulsory for a suspect to provide samples for DNA testing?

Government involvement in DNA technology – regulatory and ethical frameworks

Government involvement in DNA technology and processes is generally met with mixed reviews. Supporters believe that we need regulation and structure to ensure that this type of technology is

not misused. Critics believe that government involvement can lead to a loss of personal freedom if it is too excessive.

With the global trend for laboratories to come on to the market and take opportunity of the advancements in DNA technology and testing, the reliability of their results is vital to providing the public and legal system with accurate information. As such, it is mandatory that laboratory testing is reliable and provides a valid result. Unfortunately, this is not always the case.

Given the weighting attached to DNA evidence, particularly in criminal cases, it is important to have in place an accreditation process for laboratories, to ensure reliability, consistency and compliance with international standards.

A team from Staffordshire University visited Mauritius in November 2007 and assessed the needs of the Forensic Science Laboratory. It identified fields in which training was required: forensic awareness; expert witness training; training of staff. Over the period 28 January to 15 February 2008, a Scoping Study to develop a long term strategy for the use and development of forensic science in Mauritius was conducted with the assistance of the UK Forensic Science Service, with a view to establishing a user requirement for the laboratory, assessing forensic science

standards, and preparing a report on development issues for a long term strategy for the use of forensic science.³

The controversy over the government's involvement in DNA and related technologies will likely continue for many years to come, particularly as DNA technology becomes more advanced and mainstream. We need to continue expanding our awareness of government involvement to ensure that any interference is ethical and in the best interests of the public while also safeguarding privacy and freedom to a reasonable extent.

Bio-banks and bioethics

Genetic research and research using human tissue material has provided insight into the individual's genetic material in a way which was previously impossible, thereby allowing possibilities for the diagnosis and treatment of hereditary illnesses.

Bio-banks, i.e., systematic collections of biological samples, are important resources for health. The pooling of such resources in international scientific studies amplifies their potential scientific value. However, national and international legislation, ethical

³ Discussion Paper 'Forensic Use of DNA', Law Reform Commission of Mauritius, April 2009 (available at <http://www.gov.mu/portal/goc/lrc/files/Forensic%20Use%20of%20DNA.pdf> ; accessed on 05 June 2009).

guidelines, and a multiplicity of patient/donor interests must be addressed, as well as scientific considerations, if such research is to be successful. Pathology bio-banks are vital assets for medical care and treatment of current and future patients. In association with good clinical data they are also useful for biomedical research regarding the underlying mechanisms of human disease, and can form part of larger resources that are linked to various applications within the sphere of bioinformatics.⁴

In the debate about human bio-sampling, the interests of patients and other sample donors are to be balanced against the interests of scientists and their freedom of research. Scientists want efficient access to and use of human biological samples. Patients and other donors of blood or tissue materials want protection of their integrity. If the basic interest of scientists using human biological samples is in increasing knowledge and developing better treatments, and if the concept of ‘integrity’ is properly understood, then sample donors should also be interested in promotion of efficiency as well as in the protection of integrity. The premise of this argument is that donors of samples have interests related to the donation and use of use of samples as well as to the use of the results of the research, i.e., new medical products and treatments.

⁴ The University of Mauritius has recently been designated as the Regional Bioinformatics Node by the Southern African Network for Biosciences (SANBio), to coordinate the development and implementation of a programme for R&D and capacity building in bioinformatics for the Southern African region.

They have a role both as donors or participants in research and as end-users of the research.

The potential benefits of biomedicine and biotechnology are considerable, but this is also an area of science and medicine that is sometimes found controversial. Decisions made by scientists, by health care professionals and by policymakers must be well informed and based on knowledge and sound research. Legal experts concerned with public law and intellectual property rights, and social scientists, need to collaborate with geneticists, pathologists, and doctors in several research projects in order to seek the kind of bio-bank management that would satisfy the interests of both the research community and the general public as regards new medicines and forms of treatment, whilst protecting the integrity of the individual.

Advances in understanding and using genetics, whilst having beneficial implications relating to the treatment of genetic disorders, might also potentially contribute in the absence of safeguards to discrimination and stigmatisation.

Families of missing persons go through significant emotional and psychological upheaval, especially when they are unable to learn

about the fate of their loved ones. Through the use of DNA technology, it is now technically possible in many cases to make a positive identification of the remains through matching/comparison of profiles with personal effects or with close biological relatives of the missing person.

In the context of legislative proposals, i.e., the DNA Identification Bill, specific policy issues that need to be addressed relating to DNA sampling/profiling, its forensic use and the operation of a DNA database, include:⁵

- Safeguards with respect to DNA sampling and retention of DNA samples/profiles
- The permissible uses of the DNA samples/profiles
- Quality control of the collection, handling and analysis of DNA samples

It is interesting to note that over the period 2001 to mid-2008, DNA testing was used as a tool in crime investigation in 107 cases. These tests led to the elucidation of ten cases.

⁵ Source: Discussion Paper 'Forensic Use of DNA', Law Reform Commission of Mauritius, April 2009 (available at <http://www.gov.mu/portal/goc/lrc/files/Forensic%20Use%20of%20DNA.pdf> ; accessed on 05 June 2009).

