

A Scientific Revolution

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Many of the most important issues in the Social Sciences today are presented by advances in the physical sciences and technology. When the twentieth century is viewed in retrospect, it is likely that the assessment of its most significant developments will concern technology—particularly the discovery of the atom and of nuclear fission; the advent of informatics and the elucidation of the structure of DNA. Each of these developments presents global problems and requires global solutions. Social scientists, including lawyers, will have to respond to these challenges. They will have to do so at an international, regional and local level.

We will only be able to respond efficiently if we are aware of the developments which are occurring and if we familiarise ourselves with at least the rudiments of the science and technology which those developments reflect. Here's the rub. So rapid are the advances and so sophisticated and complex are the details of the science and the explanations of the technology, that even an informed lay person finds it difficult today to comprehend exactly what is occurring. Yet the outcomes are vital to our society, its democratic institutions, its laws and even to the survival of the human species. These are not, therefore, issues that can be left to technologists alone.

In response to the challenges of the genome, the former Conservative government in Britain established the Human Genetics Advisory Commission. It is a high powered affair. Sir Colin Campbell, Chairman of the Commission has described the way in which the Commission is obliged, under its terms of reference, to keep under review scientific progress at the frontiers of human genetics; to report to government and society on issues arising from the new developments that can be expected to have wider social, ethical and economic consequences, and to advise on ways to build public confidence in, and understanding of, the new genetics. Sir Colin describes the endeavour to bring the complex issues to a wide audience in Britain and to ensure that the Commission's advice will mirror the broad range of opinion which these complex and sensitive questions evoke.

There is no such body in Australia. The closest we get to it is the Australian Medical Health Ethics Committee which is chaired by Professor Donald Chalmers of the Law School of the University of Tasmania. There is insufficient public debate in Australia about the genetic revolution. Most people must depend upon articles in the popular media for the rudiments of their knowledge. Inevitably, such articles tend to concentrate on highly contentious and sometimes sensational issues such as the potential for reproductive cloning of a human being. The full picture is much more complicated. Before embarking on a few of the social themes, let me sketch, as briefly as

I can, some of the general scientific background which it is essential for all of us to know.

A Scientific Primer

In 1953 two scientists, one from the United States and the other from Britain, Drs JD Watson and FHC Crick, published in *Nature* an essay that was to revolutionise understanding of the basic forms of life. Not just human life, but all forms of life. They provided a model for understanding the process of the transfer of genetic information between generations of the same organism.

This article was not, of course, the first step on the path of genetics. Even in primitive societies farmers knew the benefits of mating particular domestic animals or cross-breeding particular crops. But the early, primitive discoveries came together, and were explained, by Watson and Crick. They proposed that the basic determinates of living matter were to be found in DNA, in a structure described as a double helix. DNA was the molecule which carried the genetic code that would unlock the truth known instinctively by farmers and described in a primitive, but accurate, way by Mendel. From that moment to this, the search has been undertaken to explore the DNA and to unlock its remaining secrets.

The coincidental development of information technology presented the means which would help scientists to perform the analysis necessary to understand the control mechanisms residing in the DNA. In 1990 a group of scientists decided that they should cooperate in sequencing the entire human genome. The genome represents the complete set of genes and chromosomes of the organism. The intention of this project, which became known as the Human Genome Project, was to construct a 'high-resolution genetic, physical and transcript map' of the human being with, ultimately, a complete sequence of the genome. The outcome is the largest research project ever undertaken. The object is to determine the location of the estimated 100,000 human genes. The purpose is to provide the source book for biomedical science in the 21st century [which would] be of immense benefit to the field of medicine. The object is to understand and eventually treat many of the more than 4,000 genetic diseases that afflict mankind, as well as the many multi-factorial diseases in which genetic predisposition plays an important role.

The sequencing of genes is being performed by automatic machines of the most tremendous computer power. More than 50,000 genes have already been identified. For a majority of these, the function is still unknown. Yet gradually, in the manner of the *Rosetta Stone*, the genetic language will be deciphered. Patterns will be discovered which are distinct and which exist only in a person with known genetic conditions, such as Huntington's Disease or Alzheimer's Disease, Cystic Fibrosis and so on. Similarly, distinct patterns will be seen in the case of persons who are bald; those who are tall; those who have blue eyes; those who are disposed to obesity or other

genetic propensities. One by one, and by a process of reasoning, experimentation, logic and elimination, the encyclopaedia will be rendered into a language which human beings can understand. This is the mighty challenge of the Human Genome Project. It is already happening. Scarcely a week goes by without some new discovery which allows scientists to point to a particular gene or sequence of genes as being the cause of, or related to, the presence of some genetic condition in the human subject.

The Ethical Choices

Take the following problems, stated in very general terms, which the foregoing scientific developments present for ethical choices and, ultimately, for the law and social controls.

1. **Medical therapies:** Scientists are now discovering the genes which 'trigger' various genetic diseases which, in turn, constitute a large part of the inherited causes of the suffering of humanity. For example, the genes which express themselves in Huntington's Disease, a serious affliction. Their discovery permits the conduct of extremely accurate tests which can now identify those people who carry and may transmit this genetic condition. That knowledge would, theoretically, in combination with prenatal tests and abortion, permit the future elimination of carriers of Huntingtons. Is this desirable? Can it be distinguished from the abortion of a foetus with Down Syndrome? Where does this process of medical elimination of the results of 'defective' genes begin and end? Is there a less life-destructive means of using the genetic information to delay the onset or diminish the symptoms of Huntington's disease whilst respecting the life of a person born with those genes or others like it?
2. **Criminal Law:** For the lawyer, the discovery of genetic causes of disorders and of some antisocial conduct may have implications for the future. The criminal law is built upon a general hypothesis of free will. For the crime to be established it is normally necessary to prove both the act of the accused (*actus reus*) and the will (*mens rea*) occasioning that act. But what are the implications for society of discovering that, in some cases at least, for some people, the act is practically nothing but the product of a genetic characteristic? Can we persist, in all cases, with the unquestioned hypothesis of free will in the face of scientific knowledge which casts doubt upon it?
3. **Privacy and Confidentiality:** The basic rule of the healthcare professions has long been respect for the confidences of the patient. This rule goes back at least to the Hippocratic Oath. It existed in ancient civilisations. But when a disorder is of a genetic characteristic, is the 'patient' the individual or the entire family? Does a 'family' in such circumstances

have a right to override the wishes of the patient and to secure data about the patient's genes relevant to genetic features important for them all? Should a patient have a right *not* to know the determinants of his or her future medical conditions?

4. *Third Party Interests:* This last question leads to the rights of third parties. Should an employer have a right to require an employee to submit to genetic testing to show, with greater perfection, the likely future health status of the employee? Should an insurer be entitled to secure a detailed genetic profile of the insured? Until now, insurance has generally involved the sharing, within the community, of the risks attached to medical conditions which are largely unpredictable. If such conditions can be predicted with perfect or near perfect accuracy, would that not shift the scales unfairly to the advantage of insurers? Yet, where insurers can require those seeking insurance to submit to old-fashioned medical tests, is it sensible to close off knowledge of the best medical information that may be made available by genetic tests?

5. *Patenting genes:* One of the key issues of genetic research concerns the desirability of permitting the patenting of human genes or their sequences as the basis for future therapeutic applications. Of course, in every country, the patentability of such matter depends upon the terms of the local law on intellectual property protection (patents, copyright etc). That law is itself normally the product of national legislation and is often influenced by international law. At conferences on the genome, strong views are commonly expressed by participants from developing countries and elsewhere about this topic. They urge that the human genome is the common heritage of humanity. That it belongs to the human species as a whole - some say to God - and not to private corporations engaged in research, however potentially beneficial such research may prove to be. They point to the fact that Watson and Crick never attempted to secure the slightest commercial advantage for themselves from their discoveries.

International developments

There are at least two important international institutional responses to the foregoing developments, apart from those which exist in learned academes, universities, national bioethics commissions and other local institutes. I am associated with each of them. One is the Ethics Committee of the Human Genome Organisation - the international scientific association which is supervising the Human Genome Project. The other is the International Bioethics Committee of UNESCO. The latter Committee produced the *Universal Declaration*. It was adopted by the General Conference of UNESCO in November 1997. It represents an endeavour to state the basic

principles which should provide the ethical and legal framework within which national responses may be developed to the challenge of the genetics revolution.

The main substantive provisions of the new *Declaration* insist upon the requirement of rigorous and prior assessment of potential risks and benefits for any research, treatment or diagnosis affecting an individual's genome. In every case, the prior free and informed consent of the person concerned must be obtained. It is specifically recognised that each individual has the right to decide whether or not to be informed of the results of genetic examination. No one is to be subjected to discrimination based on genetic characteristics such as will infringe that person's human rights, fundamental freedoms and human dignity.

The Social Science Approach

The issues which I have outlined may seem daunting. It is necessary for social scientists to respond to such problems. It is also necessary for them to develop the institutions and methodologies which can respond efficiently and the frameworks within which national responses can be rationally worked out.

Those responses will be founded on a good knowledge of genetic science. They will involve multidisciplinary dialogue such as is achieved in the United Kingdom Commission which Sir Colin Campbell leads. They will require us to think positively as human beings and as social scientists about the potential of genetic science to relieve suffering and to save people from premature death.

Social scientists will teach the importance of involving the public in discussion about the legal and ethical choices which genetics presents. They will explain the difficulties of securing agreement, on a global level, when there are so many different regimes of religious and ethical principles. Thus global prohibitions on experimentation with foetal material are unlikely to succeed. Whereas some Christian groups regard life as beginning at the very instant of conception, Judaism and Islam consider that the embryo does not acquire human characteristics until after 40 days. Other religions and philosophies, and humanists, may choose to recognise an even later time. Clearly, it is important to develop global institutions and to provide global solutions to a problem which literally concerns all humanity, involved as it is with nothing less than the future makeup of the human species. The highest common denominator of agreement may not be very high.

A Few Conclusions

Human beings are moral creatures. They are also gregarious. They group themselves in societies, ultimately international society. The genetic revolution will be overwhelmingly for the benefit of humanity. It will provide the universal textbook for medical science in the next century. It is happening. It is happening quickly.

Important social, ethical and legal challenges are presented. It is vital that the best scientific minds should be engaged upon these problems and challenges. Such exciting developments deserve to be shared with all people. Social scientists have a responsibility to promote, both in their own countries and internationally, a regime which is equitable, respectful of the dignity of the individual and mindful that the individual is always much more than a collection of his or her genes. These are topics which, in the future, will increasingly engage the attention of our Academy.

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