Ethical Issues in Genetic Testing

by **Pierre Mallia** *MD MPhil PhD MRCP FRCGP*
Director, Centre for Bioethics and Patient Advocacy

The question has often been asked whether there is anything special about genetic tests – a topic known as Genetic Exceptionalism. Genetic Essentialism, is conversely, whether 'we are our genes'. Regarding the latter statement, everyone would agree that our environment has a lot to do with what we are – from the place where we live to the way we are brought up. However most scientists agree as well that there are boundaries which limit 'what we are', and these boundaries are usually genetic. If this is the case, then genetic exceptionalism is perhaps true, as a genetic test can tell us something about each and every person, which a normal test cannot. A cholesterol test can tell me whether I have hypercholesterolaemia or not; a genetic test (if developed) may tell whether I am prone to develop it. Genetic tests are thus *predictive*; moreover they may involve other people, close relatives, who may not wish to know about their status and yet still be directly affected by insurances, employment issues, etc.

UNESCO[1], WHO[2], Council of Europe[3], European Commission[4] and many other bodies have thus issued documents relating to genetic testing. Whilst UNESCO, for example takes genetic exceptionalism as a reality, the European Commission considers it as non-existent. *Yet,* even the European Commission has seen fit to issue statements and recommendations which are interestingly parallel to those of UNESCO. They admonish, for example, against discrimination based on genetic testing and recommend caution because of the special nature of the informed consent process and population screening. It is therefore difficult not to see anything special about genetic testing, especially when seen from the non-medical point of view.

Most documents are focusing on genetic testing in adults, and issue guidelines accordingly. For example, many do not envisage problems with the use of genetic tests for forensic use – creating a database with all genetic fingerprints may however be frowned upon. Conversely, many see the positive in research areas, such as pharmacogenetics, whereby we would not have to wait and see the effectiveness of a drug or its side effects before we move on to a more appropriate one for the patient.

Genetic testing can however be done at various levels. In the pre-zygote phase (defined here as the stage before the two pro-nuclei meet), one can make use of the genetic material of the second polar body to diagnose severe genetic diseases, such as Huntington's Disease. However, it is still highly debateable whether at this stage one has an individual human, once the genetic material has not yet formed. If this is allowed, one would certainly have to contemplate using technologies such as In-Vitro Fertilization for families at risk of serious genetic diseases, rather than for infertility alone.

Of course genetic tests can be done later in pregnancy and in countries, such as the UK, a severe genetic defect in a foetus can lead to a legal termination of that pregnancy. Even doctors working in the UK have to be careful, irrespective of their moral viewpoints, for whether one is in favour or not of such legislation, one still has obligations as to how to deal with someone asking for termination of pregnancy. There are issues beyond the abortion itself.

Disability rights movements have offered great opposition for this kind of 'selective abortion'. Perhaps what seems to be contentious is abortion itself, rather than the fact of aborting a fetus with a foreseen disability; even disabled people themselves may want to see their disability eliminated. It is the means rather than the end which seems to be the problem.

An outcry of this sort was seen recently in Cyprus[5], where the incidence of thalassaemia was high. The state, with the cooperation of the Orthodox Church, successfully attempted to reduce thalassaemia by obliging couples suffering from thalassaemia or who are carriers for directive counselling before marriage, and offering termination of pregnancies to married ones. Whilst the WHO condoned this as an effective public health measure, UNESCO condemned it. Indeed, from a purely academic point of view, one cannot equate measures to improve the 'health of the public', with 'public health'. They may sound similar, but they are not the same. If all persons in a population are healthy, the health of the public is fine; but there may still be public health issues – such as smoking or, in our case, environmental factors that will affect our genes. It is debatable whether a measure aimed therefore to improve spending of public funds is 'public health', although traditionally (at least locally) it is public health officials within departments of health who are involved in these decisions.

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When it comes to Genetic health then, we are concerned with future generations as well as ourselves. Genetic intervention can be done on somatic cells, as well on germ-line cells. Nevertheless a healthy discussion of genetic testing and engineering must keep its feet on the ground. Such rhetoric as 'body spare parts' or 'selecting a baby with blue eyes', may indeed not be fictional, but is probably far from what science wants to achieve – a cure for genetic diseases. The scope of documents and working parties therefore focuses on proper ways to store samples, define what in fact is a genetic material (not necessarily all tissue samples are), and what in fact is data. Obtaining benefit from genetic research has to be balanced with public scrutiny in order to maintain trust in science. The media may play an important role in educating the public, but often, what is not sensational does not make good news. It is curious for example, that scientists revealed news about their cloning of 'Dolly' one year before actually succeeding in doing so. But it was the *picture* of the live animal which created the sensation. The morale is to use media with caution.

References

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