

Chapter 16

Genetic Testing and Protection of Genetic Privacy: A Comparative Legal Analysis in Europe and Australia

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ABSTRACT

Progress in the field of biomedical science has made it possible to obtain greater knowledge of the human genome and the nature of genetic disorders. Thanks to these advances, doctors now have the tools to diagnose certain disorders, and to carry out genetic tests to determine increased risks of developing other illnesses and of passing them on to future generations. In addition to the classic single gene disorders (like hemophilia and sickle cell anaemia), susceptibility genes are also being identified for genetically complex diseases, including many types of cancer, Alzheimer's disease, diabetes and other illnesses (House of Lords, 2009, p. 8). We can look toward a future where genetic test results are an important part of every healthy person's medical file.

INTRODUCTION

Currently, genetic testing has developed to the extent that doctors can pinpoint missing or defective genes. However, in practically all cases, treatments for those diseases are still far off.

Despite the paucity of available treatments for genetic conditions at the current time, genetic testing still has an important social value in informing people about genetic risk factors for them and their offspring (both present and future). For some, such as those with an increased risk of cancer (e.g. colon or breast cancer), regular surveillance can be undertaken which can be beneficial in ensuring early diagnosis to maximize the effective-

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ness of available treatments. Genetic testing of individuals can bring to light important personal and family information about current and future health, including mental health, even though this may be limited to giving advance warning of a propensity or predisposition to certain disorders, or information on reproductive capacity and the future health of offspring. Knowledge of such matters gives individuals the capacity to plan for the future and to avoid lifestyle choices that may exacerbate the risk of adverse health outcomes. And, of course, those who receive a negative test result will have their concerns about developing a genetic condition in the future or passing on genetic risk factors to their offspring alleviated.

But genetic testing could also have significant detrimental social impacts. Increasing knowledge of the human genome and expanding opportunities for genetic testing raise new challenges, even though diagnosis of genetic risk factors is not of itself a new field (having long been available by means of mapping family histories for genetic diseases). What has changed is the *means* by which genetic information is available and also the *extent and quality* of information which can now potentially be obtained as a result of the advancements in relation to genetic testing (Otlowski, 2002b). While family history remains an important consideration in assessing the risk of developing a genetic disease, or a disease which has genetic as well as environmental triggers, genetic testing provides higher quality information in the sense that it can actually identify the genetic mutations that provide those genetic triggers. Hence, while genetic testing does not provide certainty about the onset of disease—neither its inevitability nor its severity—it does enhance the capacity to measure risk. Such information provides knowledge of highly personal aspects of the tested individual and directly affects his or her innermost sphere. The personal nature of this information means that particular care needs to be taken in establishing appropriate regulatory frameworks for dealing with it.

Unless appropriate procedures are put in place to protect this information, there is a risk that

individuals may simply choose to refuse testing, even though it might otherwise provide significant benefits to them and their families (Keogh, 2009). The role of the law in this area should be to provide an appropriate balance between protecting the interests of individuals who undergo testing and taking into account other legitimate interests.

The aim of this article is to point out the main dilemmas in the field, with specific focus on the issues associated with genetic privacy, centered around three key questions:

1. How is the protection of genetic privacy recognized by law?
2. Does a person who undergoes genetic testing have a right to know test results as well as a right not to know?
3. To what extent can genetic test information be used outside of the confidential doctor-patient relationship by third parties including:
 - Other healthcare providers;
 - Other family members; and
 - Insurers and employers.
4. What new issues does direct-to-consumer testing raise?

The article starts by considering the available evidence on the extent to which these dilemmas are affecting members of the public in their decision-making about genetic testing and use of their genetic information. The article then examines the solutions that have been offered to these dilemmas within the international, European and Australian regulatory frameworks.

The rationale for examining these issues in the European context is that the European framework for personal data protection was established much earlier than in other jurisdictions,¹ and has undergone much greater scrutiny at the policy level. As such, the European approach provides one possible model that might be adopted much more broadly, especially if we take into consideration that the key legislative development in the field

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