Chapter 14
The Regulation of Genetic Testing and the Protection of Genetic and Medical Information in Singapore

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ABSTRACT

In the decades since its independence in 1965, the transformation of Singapore's economy and its transition to a relatively developed economy has also in like manner transformed its health care system, and of the demands made of it. The emergence and availability of new medical technologies has put into sharp focus many novel legal, ethical as well as social issues. This chapter looks at how Singapore has attempted to respond to issues thrown up by genetic testing and screening technologies. A particular focus of this chapter will be the tension between privacy concerns, and the imperatives of access for biomedical research, given that biomedical research has been championed by the Singapore government as one of the future leading sectors of the economy of Singapore. This chapter also examines Singapore's approach to the question of "genetic exceptionalism:" Does genetic information possess special qualities or attributes that remove it from the realm of ordinary personal information, and which thereby demands special treatment and protection? In this context, the impact of the doctrine of genetic exceptionalism on industry (in this case the insurance industry) is examined.

THE BACKGROUND

On November 25, 2005, the Singapore Bioethics Advisory Committee released a Report entitled "Genetic Testing and Genetic Research" (The Singapore Bioethics Advisory Committee, 2005).[2] In the Report (the "Genetic Testing Report"), the BAC laid down ethical guidelines for an array of genetic testing procedures and for genetic research. A year and a half later, the BAC released a further Report entitled "Personal Information in Biomedical Research" (The Bioethics Advisory Committee, 2007) ("the Personal Information Report") which *inter alia* took up and expanded on some of the themes first examined in the Genetic Testing Report. Both the Genetic Testing

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Report and the Personal Information Report was subsequently accepted in full by the Singapore Government, and (through the mechanism which will be explained below) effectively assumed the status of binding professional guidance for the medical profession as regards genetic testing and screening procedures, and on matters on the use of genetic testing and genetic information used in research.

Some contextual background may be useful at this point for a proper appreciation of the Genetic Testing Report and the Personal Information Report, and on their impact and implications[3]. Towards the end of 2000, the Singapore Cabinet decided to establish a national-level agency to establish guidelines, and to make recommendations for supporting legislation and regulatory structures for the development of biomedical research in Singapore.

To this end, the Singapore Bioethics Advisory Committee was appointed by the Cabinet. Applying an approach commonly employed by the government in Singapore, its constitution was and continues to be that of a committee of experts[4] (the majority of which were drawn from the medical, legal and biomedical research sectors) without any separate official or legal identity of its own, reporting and making its recommendations to a committee of ministers charged with steering the Government's plans for the development of the biomedical industry and research sector in Singapore[5]. One of the impetus for the establishment of the BAC was no doubt the launch by the Singapore Government of the Singapore Biomedical Sciences Initiative (BMS Initiative) in June 2000; the vision was for Singapore to be the "Biopolis of Asia," with the BMS Initiative targeted at the development of the biomedical industry and research sector "as the fourth pillar of Singapore's industry cluster, alongside electronics, chemicals and engineering."[6]

That the BMS Initiative has had a profound impact on the reshaping of the present and future of the Singapore economy is not in dispute. For 2007, the biomedical sector's contribution to the manufacturing sector amounted to S$24 billion (US$17 billion as at January 2010 exchange rates), and accounted for 6% of Singapore's GDP (Agency for Science, Technology and Research, 2008). Currently, by far the great bulk of the contribution of the biomedical sector comes from pharmaceutical manufacturing, as opposed to biomedical research (including biomedical research services). The Singapore Government, however, recognizes that research is a fundamental support pillar of the biomedical sector, and to this end has poured considerable resources and funds into developing the biomedical research services sector. The most visible result of this push towards the development of biomedical research in Singapore has been the construction of the Biopolis complex at the new new one-north [sic] development situated in close proximity and designed as a complement to the two existing Science Parks, the Fusionopolis complex, the National University of Singapore and the National University Hospital.

From a regulatory and legal point of view, however, the breathtaking pace of these economic and physical infrastructural developments has not been matched by developments in the formal law and the regulatory structure. Perhaps surprisingly, Singapore did not until the establishment of the BAC in 2000 have a national-level body aimed specifically at the development and coordination of the ethical governance of biomedical research. Until the establishment of the BAC, that responsibility was in part addressed by the National Medical Ethics Committee (the NMEC).

The NMEC was established in 1994 by the Ministry of Health to identify and advise the Ministry on, among other things, "…the prevailing ethical issues relating to public health, medical practice and research in Singapore [and] … on the potential ethical issues which may occur in Singapore based on the trends in other developed countries" (National Medical Ethics Committee, Singapore, 1998). Although most of the work of the NMEC dealt with matters of medical practice,