

available at www.sciencedirect.comwww.compseconline.com/publications/prodclaw.htm

**Computer Law
&
Security Review**

Bioinformatics and genetic privacy: The impact of the Personal Data Protection Act 2010

Ida Madieha Azmi

International Islamic University Malaysia

ABSTRACT

Keywords:

Bioinformatics
Genetic privacy
Personal Data Protection Act 2010
DNA database
Data mining
DNA profiling

Bioinformatics refers to the practise of creation and management of genetic data using computational and statistical techniques. In Malaysia, data obtained from genomic studies, particularly for the purpose of disease identification produces a tremendous amount of information related to molecular biology. These data are created from DNA samples obtained from diagnostic and research purposes in genomic research institutes in Malaysia. As these data are processed, stored, managed and profiled using computer applications, an issue arises as to whether the principles of personal data privacy would be applicable to these activities. This paper commences with an illustration of the salient features of the Personal Data Protection Act 2010. The second part analyses the impact of the newly passed Personal Data Protection Act 2010 on the collection of DNA sample, the processing of data obtained from it and the profiling of such data. The third part of the paper considers whether the various personal data protection principles are applicable to the act of DNA profiling and the creation of bioinformatics.

© 2011 Prof Dr Ida Madieha Azmi. Published by Elsevier Ltd. All rights reserved.

1. Introduction

Bioinformatics refers to the science of informatics as applied to biological research. Informatics is the management and analysis of data using advanced computing techniques. Textbook writers use the term bio informatics to refer the science of integrating, managing, mining and interpreting information from biological data sets. The three main components in bioinformatics are:

- The creation of databases allowing the storage and management of large scale data sets
- The development of algorithms and statistic to determine the relationship among members of large data sets
- The use of these tools for the analysis and interpretation of various types of biological data, including DNA, RNA and protein sequences, protein pictures, gene expression profiles and biochemical pathways.

2. Genomic studies, the creation of DNA databases and genetic privacy

Genetic information is important and unique for many reasons. Genetic information can be symbolically coded at different levels of abstraction: either for medical reasons such as tests for the presence or absence of a particular allele test for deoxyribonucleic acid (DNA) sequences near the genes (genetic markers) and tests for gene products or proteins. Genetic information can also be used for solving crimes such as genetic finger printing. Paternity testing is another area in which a big volume of genetic information has been generated. The uniqueness of genetic information is that it not only defines the personal identity of a person but also the social groupings for which he belongs such as the family, the disease group and the ethnic group. Thus, in relation to disease association, it is possible that one's

genetic information may reveal his/her family's predisposition to certain diseases.¹ Some diseases are X-linked disorders, or recessive disorders that do not pose harm to the health of the carrier. In this way, one's genetic information may also be predictive of the health of others rather than oneself. In most instances, genetic information on X-linked disorders could not be totally anonymised. Another uniqueness of genetic information is that it is imprecise; it is of most an indication of one's predisposition of certain diseases, but not necessarily an absolute diagnosis of the state of health of a person.

In relation to genetic research, there may be two different types of privacy interests; informational privacy and spatial privacy. Laurie defines informational privacy as the denial of access to personal (health) information to those to whom the information does not relate. Spatial privacy concerns the sphere of the self – a 'zone of privateness' surrounding the individual that cannot and should not be invaded without due cause. This spatial privacy can be invaded by unwarranted physical contact.² In this context, the conduct of genomic research in Malaysia would implicate both types of privacy. Could bio specimens obtained for treatment be used discretely for research such as disease association or migration patterns? Could excess embryos created for pre implantation genetic diagnosis used for research? If DNA samples are taken without consent, that would amount to a breach of spatial privacy. However, if the DNA analysis created for treatment is used for research, that act would amount to a breach of informational privacy.

This paper examines the applicability of personal data protection principles under the Personal Data Protection Act 2010 to the collection of genetic data and the consequent processing and compiling of such data in electronic databases.(Table 1).

3. Privacy law in Malaysia prior to PDP 2010

Malaysia's attempt to introduce personal data protection laws started in 2000 with a proposed draught bill. The Bill which incorporated the European standards on data protection faced tremendous opposition from the industry and was archived. Some sectors in Malaysia were already subjected to sector-based consumer confidentiality requirements set under several legislation, such as the Communication and Multimedia Act 1998, the Telemedicine Act 1997, the Private Healthcare Facilities and Services Act 1998. The Banking and Financial Instrument Act 1989, the Insurance Act 1996, the Offshore Banking Act 1990. The Offshore Insurance Act 1990, the Child Act 2001, the Employment Information Act 1953 and the Payment Systems Act 2003. After the proposed Bill was archived, in 2009 a new proposed Bill was tabled before the Parliament and 2010 the Bill was passed. The 2010 Act has diluted several requirements:

¹ Urs Dahinden et al, 'Dilemmas of Genetic Information', in George Gaskell & Martin W. Bauer, *Genomics and Society: Legal, Ethical & Social Dimensions*, (2006) Earthscan, UK & US.

² Graeme Laurie, *Genetic Privacy: A Challenge to Medico Legal Norms*, Cambridge University Press, 2002, p. 64.

Table 1 – Comparison between the 2000 Proposal and the 2010 Act.

| Principle | 2000 Proposal | 2010 Act |
|-----------|---|-----------------------|
| 1 | Manner of Collection of personal data | The General |
| 2 | Purpose of Collection of personal data | The Notice and Choice |
| 3 | Use of personal data | The Disclosure |
| 4 | Disclosure of data | The Security |
| 5 | Accuracy of personal data | The Retention |
| 6 | Duration of retention of personal data | Data Integrity |
| 7 | Access to and correction of personal data | Access |
| 8 | Security of personal data | |
| 9 | Information to be generally available | |

- Opt in requirement for collection of personal data.
- Mandatory registration requirement for data user.
- Prohibition against data matching unless with the consent of the data subject.
- The scope of the Act.
- The applicability of the Act.

4. Salient features of the Personal Data Protection Act 2010

4.1. What is personal data?

Under the Act (section 4), "personal data" means any information in respect of commercial transactions, which:

- is being processed wholly or partly by means of equipment operating automatically in response to instructions given for that purpose;
- is recorded with the intention that it should wholly or partly be processed by means of such equipment; or
- is recorded as part of a relevant filing system or with the intention that it should form part of a relevant filing system.

From that provision, personal data used for non commercial purposes would not be falling within the purview of the Act. A "commercial transaction" is defined under the Act to mean any transaction of a commercial nature, whether contractual or not, which includes any matters relating to the supply or exchange of goods or services, agency, investments, financing, banking and insurance, but does not include a credit reporting business carried out by a credit reporting agency under the Credit Reporting Agencies Act 2009. The express reference to commercial transaction excludes a wide range of personal data collected for non commercial purposes such as statistics and this would probably include research as well. The express exclusion to the credit reporting agencies were attributed to the fact that this sector would be subjected to a separate rules and regulations. Another important

Download English Version:

<https://daneshyari.com/en/article/467510>

Download Persian Version:

<https://daneshyari.com/article/467510>

[Daneshyari.com](https://daneshyari.com)