
Facing Up to the Human Variome Project: Analysis on the Adequacy of Malaysian Laws in Dealing with the Legal Challenges Arising

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ABSTRACT: Malaysia is now a member of the international Human Variome Project (HVP), a project initiated to collect and share genetic data obtained worldwide that cause human diseases. In this regard, Malaysia has established the Malaysia Human Genome Variation Consortium known as the 1Malaysia Human Genome Variation Consortium (1Mhgvc) to act as the Malaysian node for the HVP. The 1Mhgvc has initiated steps to collect genetic data from Malaysians with the aim to finding genetic data that cause diseases such as thalassemia, cancers and other genetic disorders. While this project will help revolutionise the healthcare industry in Malaysia by saving lives and reducing medical costs, its arrival is not without ethical and legal concerns. The possibility of genetic discrimination and the issue of individual privacy cannot be undermined when genetic data from individuals are gathered for this purpose. Law, therefore, must be able to keep abreast with this advancement by providing adequate tools to safeguard the interests of individuals concerned and society at large. This forms the crux of this paper where two main issues arising from the Human Variome Project namely, genetic discrimination and individual privacy will be critically analysed. It will be determined whether the existing laws in Malaysia are sufficient to address these possible concerns. In doing so, laws from other jurisdictions will be examined and used as a benchmark in proposing for new laws and policies (if necessary) to be adopted within Malaysian legal framework.

KEYWORDS: *Bioethics; Human Variome Project; Genetics*

INTRODUCTION

The Human Variome Project (HVP) was launched in Melbourne, Australia in 2006 with the objectives of identifying and collecting genetic data from individuals from all countries. The main task of the project can be succinctly described as, "sharing data-reducing disease" (Maija R.J. Kohonen-Corish, 2013). Under this project, genetic data are gathered and analysed to determine the possibility of an individual developing any of the known diseases so that preventive steps can be taken to eliminate the disease before it can occur (Atif AB, 2010). According to Dr. Richard Cutton (2013), the founder of HVP, the project targets for every country to collect data in their countries and make them publicly available worldwide. He explains, "We are trying to get people to put their data in and make it publicly available around the world so that people can use the data..." (New Straits Times, 2013).

Malaysia is now a member of this project and has established the Malaysian Human Genome Variation Consortium known as the **1Malaysia Human Genome Variation Consortium (1Mhgvc)** to act as the Malaysian node for the HVP (Atif AB, 2010).¹ In 2013, it was reported that the 1Mhgvc has managed to collect genetic data from over 1000 individuals in Malaysia. These genetic data is analysed to predict the probability of the individuals developing diseases such as Thalassaemia and 2000 other genetic diseases (New Straits Times, 2013). Cutton (2013) believes that this project will revolutionise the healthcare industry in Malaysia by reducing budget for medical care.

¹ See <http://www.humanvariomeproject.org/>

Although this project is well-intentioned and applauded for its known advantages, its arrival is not without ethical and legal dilemmas. The concerns on individual privacy and the possibility of genetic discrimination are the main issues arising when genetic data from individuals are gathered for this purpose. These are the overarching issues that this paper seeks to address and analyse.

HVP AND GENETIC PRIVACY

When genetic data is stored, concerns on the degree of privacy that can be accorded to it are inevitable. The probability of the data being released to a third party such as insurance company and prospective employers cannot be undermined as it can have serious consequences such as discrimination. Thus, Dr. Zilfalil Alwi (2013), Head of Malaysian Human Variome Project Node opines that:

"We would, at one point, need to have legislation to protect the privacy of individuals or regulations to regulate the use of genetic information. (New Straits Times, 2013)"

In this regard, the extent to which Malaysian laws can protect the privacy of the genetic data gathered under this project must be evaluated. This question will be answered by examining the Federal Constitution, statutes, case laws and the duty of confidentiality under English common law. These will be examined in turn.

(i) The right to privacy under the Federal Constitution

Although there is no express provision in the Federal Constitution (FC) on the right to privacy, its existence may be implied under the guise of the right to personal liberty under article 5(1)². In an obiter judgment, Gopal Sri Ram J in **Sivarasa Rasiah v Badan Peguam & Anor [2010] 3 CLJ 507** stated:

"It is patently clear from a review of the authorities that 'personal liberty' in art 5(1) includes within its compass other rights such as the right to privacy." (p. 591)

Hence, it may be argued that the right to privacy is protected in the FC as a component of the right to personal liberty under article 5(1). Additionally, in **Liew Cher Pow & Ors v Pua Yong Ying & Anor. [2011] 1 LNS 1528**, the High Court vehemently stated that:

"There is no specific provision in the Federal Constitution guaranteeing the right to privacy...the fact that the right to privacy has not been specifically provided does not preclude a Court of law from holding that such a right exists." (p. 1528)

The lack of an express provision in the FC on the right to privacy has not prevented Malaysian courts from acknowledging the existence of such a right as valid legal claim. This contention is illustrated from several case laws decided in Malaysia which are discussed below.

(ii) Malaysian courts and the right to privacy

Several judicial decisions have emerged in Malaysian courts that indicate the protection accorded to individuals' right to privacy. In these cases, the courts have awarded damages to the Plaintiff in circumstances where their personal data such as personal photographs were misused by the Defendant. This was seen in **Maslinda Ishak v Mohd. Tahir Osman & Ors [2009] 6 CLJ 653** where the Court of Appeal affirmed the High Court's decision that allowed the Plaintiff's claim for breach of privacy. Here, the Plaintiff's claim was grounded upon the Defendant's conduct in capturing her photographs while urinating in a motor vehicle. This decision can be

² Article 5(1) of the FC reads, "No person may be deprived of his life or personal liberty save in accordance with the law."

construed as recognition by the Malaysian court on the right to privacy as a cause of action in law. **Maslinda Ishak** was referred to and followed in **Lee Ewe Poh v Dr. Lim Teik Man & Anor.** [2011] 4 CLJ 397. In **Lee Ewe Poh**, the Plaintiff, who was a patient of the Defendant, claimed that her right to privacy has been violated by the Defendant's conduct in photographing her private part during an operation. The Defendant argued that the Plaintiff's cause of action for breach of privacy is flawed on the grounds that breach of privacy is not an actionable tort under English common law and thus, does not constitute a valid cause of action in Malaysia by virtue of section 3 of the Civil Law Act 1956.

In finding for the Plaintiff, Chew Soo Ho JC cited **Maslinda Ishak** and remarked:

"Although Maslinda Ishak's case is not directly on point, the fact remains that the High Court in so finding has departed from their old English law that invasion of privacy is not an actionable tort and our Court of Appeal indirectly, though this issues was not canvassed, seems to endorse such cause of action when the pleadings specifically referred to and the Court of Appeal did not overrule invasion of privacy as a cause of action on grounds that it is not in line with English law." (p. 405)

Therefore, the High Court concluded that breach of privacy is a valid cause of action under Malaysian common law. The inclination towards recognising the right to privacy by Malaysian courts is observed and acknowledged in **Liew Cher Pow & Ors v Pua Yong Ying & Anor.** [2011] 1 LNS 1528. Vernon Ong acceded that:

"Malaysian courts are leaning in favour of recognising the right to privacy. Indeed, the categories of such rights are not closed and may expand with new emerging trends and changing societal condition."(p. 1528)

Finally, the right to privacy has been successfully endorsed as an actionable cause of action in **Sherinna Nur Elena bt Abdullah v Kent Well Edar Sdn. Bhd.** [2014] 7 MLJ 298. Although the Plaintiff failed in her action for violation of her privacy, the Court took notice and affirmed the Malaysian courts' stance in recognising breach of privacy as an actionable wrong.

The strain of cases discussed above illustrates the incorporation of the right to privacy as a legal right under Malaysian common law. Where the privacy of personal items in individuals lives such as photographs are violated, the courts have not hesitated in awarding damages to the victim. It can, thus, be inferred that genetic data obtained under HVP will also be protected and compensated should its privacy be violated by the data handler. The protection to the privacy of the genetic data is further enhanced by the duty of confidentiality under English common law.

(iii) Duty of Confidentiality under English Common Law

Medical personnel handling the genetic data are subject to the duty of confidentiality under English common law. They may be liable under the tort of negligence if their negligent disclosure of data causes foreseeable harm to the individual. In **AG v Guardian Newspapers (No.2)** [1990] AC 109, Lord Goff held that:

"The duty of confidence arises when confidential information comes to the knowledge of a person in circumstances where he has notice, or is held to have asked, that the information is confidential, with the effect that it would be just in all the circumstances that he should be precluded from disclosing the information to others."(p. 281)

In United Kingdom, this duty of confidentiality is incorporated into the Data Protection Act 1998. Schedule 1 of the Act contains eight data principles including the principle that "all personal data must be processed fairly and lawfully." Malaysia has, in 2013, enforced her own Personal Data Protection Act 2010 that also encompasses the duty of confidentiality.

(iv) Personal Data Protection Act 2010 (PDPA 2010)

The collection and processing of genetic data in the conduct of a research such as HVP comes within the ambit of the PDPA 2010. Genetic data of the participants may be included within the definition of "sensitive personal data" defined in section 4 of the Act.³ Generally, in safeguarding data privacy, PDPA laid down seven principles that must be observed by individuals handling the data. These principles include the General Principle, the Notice and Choice Principle, the Disclosure Principle, the Security Principle, the Retention Principle, the Data Integrity Principle and the Access Principle.⁴ The Disclosure Principle, for example, explicitly requires the consent of the data owner before the data can be disclosed to any party.⁵

Collecting genetic data for the purpose of HVP arguably falls under section 40(1) which specifically provides for the conditions to be fulfilled for sensitive personal data to be allowed for processing. Section 40(1) (b) elaborates the situations in which the processing of sensitive personal data is permitted and this includes:

"(iv) For medical purposes and is undertaken by-

(A) a healthcare professional; or

(B) a person who in the circumstances owes a duty of confidentiality which is equivalent to that which would arise if that person were a healthcare professional;..."

From the above provision, it is observed that privacy of genetic data obtained for the purpose of HVP is protected under the PDPA 2010. The party involved in collecting genetic data for HVP arguably falls within subsection (A) and/or (B) above where the duty of confidentiality is imposed upon him. Furthermore, section 40(1) (a) duly requires for explicit consent to be obtained from the data owner before such data can be processed.

(v) HVP and Genetic Privacy: Concluding Remarks

This section has demonstrated that Malaysian laws provide for adequate safeguards for the privacy of genetic data gathered for the purpose of HVP. The protection emanates from the right to privacy implicit under the Federal Constitution and is further endorsed by the courts in several cases discussed earlier. Additional protection is also available from the English common law of duty of confidentiality which has been incorporated into the PDPA 2010. Although the concern on genetic privacy may be confidently dismissed, another arising apprehension on HVP namely the possibility of genetic discrimination must be carefully evaluated. The extent to which Malaysian laws guard against possible discrimination based on individual genetic condition is examined below.

HVP AND GENETIC DISCRIMINATION

If an individual is diagnosed with faulty genes that can lead to diseases or disabilities, he is subject to possible discrimination by insurance providers and future employer. The former may

³ Section 4 of PDPA 2010 defines "personal data" as "any personal data consisting of information as to the physical or mental health or condition of a data..."

⁴ Sections 6-12 of PDPA 2010.

⁵ Section 8 PDPA 2010. This provision is, however, subject to exceptions provided in section 39.

refuse to provide coverage for individuals with genetic predisposition to genetic diseases. Dr. Malini Tharmanason (2013), medical consultant in the insurance industry explains:

"For instance, a woman with a family history of breast cancer can opt to do a test to check if she carries the gene associated with increased cancer risk and submit the results of the gene test to the insurer to review her application. If the gene is negative, that means she does not have that particular gene, so the insurer will then offer her the critical illness policy at standard rates." (New Straits Times, 2013)

Currently, there is no legislation in Malaysia that regulates insurers on the use of genetic information in assessing applications for health insurance.

Similarly, in the workplace, discrimination may occur in that employers may be reluctant to employ individuals who are at high risk of developing diseases in order to avoid bearing medical expenses for their employees (Capron, 1990). Thus far, Malaysia has yet to pass any law that prevents discrimination based on genetic condition. The anti-discrimination provision contained in article 8(2) of the FC only protects discriminatory act by the legislature or executive,⁶ on the grounds of religion, race, descent, and place of birth or gender only.⁷ Discrimination on the basis of genetics or disability is not expressly prohibited under article 8(2). A brief look at the legal position in other jurisdictions is thus useful for guidance in filling the lacuna in the Malaysian legal scenario.

The United States (US) for instance, has enforced the Genetic Information Non-discrimination Act 2008 (GINA 2008) that prohibits discrimination by employers and insurance providers. GINA 2008 outlaws health insurance providers from denying coverage or imposing higher premiums on the grounds of genetic predisposition to genetic diseases. The Act also prevents employers from discriminating based on genetic condition in the course of hiring, termination or promotion of its employees. Other relevant statute includes the American with Disabilities Act (ADA) 1990 that specifically forbids employers from discriminating against people with disabilities. Similarly in United Kingdom, the Equality Act 2010 prevents discrimination by employers on the basis of disability.

(i) HVP and Genetic Discrimination: Concluding Remarks

Any misuse of genetic information may lead to serious consequences on the individual involved, particularly from insurance providers and the employment sector. It is thus pertinent for Malaysia to enforce adequate protection for individuals with genetic conditions against these discriminations. Specific laws against discrimination, such as GINA 2008, ADA 1990 and the Equality Act 2010 may be used as benchmarks for Malaysia in drafting her own laws and policies so that individuals are not deterred from participating in the HVP for fear of unwarranted discrimination.

CONCLUSION

The HVP initiative is applauded for the future benefits that it entails for society in reducing healthcare budget by enabling preventive measures to be adopted before a person actually develop the genetic diseases. Nonetheless, Malaysia must be more vigilant in monitoring all

⁶ See **Beatrice Fernandez v Sistem Penerbangan Malaysia** [2005] 2 CLJ 713; **Government of Malaysia v VR Menon** [1990] 1 MLJ 241.

⁷ Article 8(2) provides that, "...there shall be no discrimination against citizens on the grounds only of religion, race, descent, place of birth or gender in any law or in the appointment to any office or employment under a public authority, or in the administration of any law relating to the acquisition, holding or disposition of property or the establishing or carrying on of any trade, business, profession, vocation or employment."

possible implications of the project to its participants. The issues discussed in this paper represent the major concerns on HVP that needs to be seriously considered. On the issue of genetic privacy, a brief examination on the Malaysian legal position indicates her readiness in tackling such a concern as the privacy of the genetic data provided can be safely guarded by the provisions in the FC, PDPA 2010 and the common law. However, there is a lacuna in Malaysian laws on the issue of genetic discrimination where todate, no anti-discrimination law is available in this country. As individuals diagnosed with genetic conditions are subject to potential discrimination by insurance providers and employers should their genetic data be disclosed, Malaysia needs to enact specific laws to prevent this form of discrimination as practised in the US and UK. With adequate laws enacted as a safety tool to protect the interests of the participants of HVP, it is hoped that the project will succeed in revolutionising healthcare industry in Malaysia for the benefits of society.

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