MALAYSIAN STAKEHOLDERS' INTENTION TO ADOPT GENETIC TESTING

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ABSTRACT

Advances in genetic research have greatly enhanced our understanding of diseases and have allowed improvements in terms of practical applications such as genetic testing (also known as DNA testing). Genetic testing (GT) is a type of medical test that looks for differences in the genetic makeup of individuals. The results of the test are useful with regard to informing people as to how to make decisions with regard to managing their healthcare. The successful implementation of the technology is heavily dependent on public support and acceptance, which translates into their intention to adopt the technology. Therefore, the objective of this paper is to examine stakeholders' intention and its associated predictors with regard to the adoption of GT in Malaysia. The final version of the validated questionnaire was developed and administered to a representative samples of the Malaysian population (n=421). Two stakeholder groups were considered in the form of representatives of local healthcare providers (n=221) and patients with genetic disease or their family members (n=200). The results of the study suggested that a high level of trust in key players, followed by the technology being highly accepted on religious grounds and their perception of the technology being highly beneficial, are factors with regard to supporting GT. In addition, Malaysian stakeholders reported themselves as being moderately engaged with medical genetics, and rated the risks and issues on GT as being moderate.

Keywords: Genetic Testing, Stakeholders, Intention, Predictors, Malaysia.

INTRODUCTION

Advances in genetic research have greatly enhanced our understanding of diseases and have allowed improvements in terms of practical applications such as genetic testing (Henneman et al., 2004; Chokoshvili et al., 2017). Genetic testing (GT) (also known as DNA testing) is a type of medical test that looks for changes in the genetic makeup of individuals (Semsarian & Ingles, 2017). GT may bring potential benefits to healthcare and to society as a whole (Henneman et al., 2004). Moreover, the test has become increasingly available in medical settings as well as in a direct-to-consumer form (Sweeny et al., 2014). The result of the test will help healthcare professionals and informed patients to make decisions with regard to their health (Henneman et al., 2004). In Malaysia, medical genetic services were first introduced in 1994 at Hospital Kuala Lumpur, and were then improved through the availability of genetic counselling, genetic testing and diagnosis in the following two decades (Lee & Thong, 2013).

In Europe and the United States, most of the public are generally positive in their attitude with regard to the use of the genetic testing, and regard it as useful in terms of improving their health (Gaskell et al., 2003). However, in Malaysia, there is still a lack of research that examines the Malaysian intention to adopt genetic testing. According to Pin

(2009), for technologies to be successfully implemented within society, it requires public support and acceptance. This affects the publics' intention to adopt the technology. Moreover, numerous studies have reported that intention significantly predicts a positive relationship between intention and behaviour and action tendencies (Salleh et al., 2015). In the healthcare context, intention to uptake certain types of application is considered to be one of the most important predictors.

The multi-dimensional instruments used in this study to predict overall intention towards GT involves six factors: engagement with medical genetics, trust in key players, perceptions of risks and benefits, religious acceptance, and issue concern with regard to GT (Amin et al., 2007&2014; Mustapa et al., 2019; Etchegary et al., 2010; Henneman et al., 2004). The objective of this paper is to examine stakeholders' intention to adopt GT, and its associated predictors in Malaysia. In addition, the intention to adopt GT is considered to be an important factor with regard to the successful development of GT in Malaysia.

PREDICTORS OF MALAYSIAN STAKEHOLDERS' INTENTION TO ADOPT GENETIC TESTING

Engagement with Medical Genetics

The publics' active engagement in science and technology is considered to be of importance and relevance when it comes to successfully implementing technology (Katz-Kimchi, 2011; Ji et al., 2018). This factor consisted of a combination of three components in the form of past and intended behaviour in medical genetics, awareness of the applications of medical genetics, and knowledge of genetics and related applications. The same concept has been used by Amin et al. (2007&2014) who indicated that there is a positive relationship with perceptions of the benefit of the applications.

Trust in Key Players (Scientists, Governments & Companies)

Many past studies have reported that there is a significant positive correlation between trust and the degree of participation (Ahram et al., 2014). Generally, trust involves people having a strong expectation that other people will abide by their social norms, roles and ethical principles (Gottweis, 2002). In this study, trust refers to the respondents' readiness and confidence to rely on the information associated with medical genetics provided by experts, the government and companies. The majority of people do not have enough knowledge about the technology under consideration. Therefore, they have to rely on information which they accept on social trust to reduce the complexity of risk management decisions (Siegrist, 2000).

Perceptions of Risks and Benefits

Consumer behaviour studies have suggested that perceptions of the risks and benefits associated with technology have a directly influence on consumer responses with regard to successful acceptance of the technology (Siegrist, 2000; Giles et al., 2015; Frewer, 2017). Consumer acceptance of new technology is likely to be high if the perceived benefits in some way outweigh the perceived risks (Giles et al., 2015; Frewer, 2017). However, it is difficult to predict consumer attitudes towards the acceptance of technologies because there are highly variable in psychological, attitudinal and cultural characteristics. This is reflected in different reactions when making decisions about technology (Frewer, 2017).

Religious Acceptance

Malaysian stakeholders claim to be highly attached to their religion (Amin et al., 2017). Religion is an important factor that may influence public opinion (Allum et al., 2014). Numerous studies have reported the significant effect of religion and religiosity on public views with regard to the acceptance of new technologies (Amin et al., 2017). However, past studies have reported that there has been little research on genetic testing in terms of examining the effect of religion on genetic risk perception and decision-making (White, 2009). Meanwhile, religious acceptance influences public participation with regard to biospecimen donation for research purposes (Ahram et al., 2014).

Issues of Concern with regard to Genetic Testing

According to Motulsky et al. (1994), genetic testing could raise some serious issues related to medicine, public health and social policy. In Europe, despite positive attitudes toward GT, the public has raised some concerns with regard to testing such as with regard to discrimination related to gene carriers, abortion, employment and insurance (Etchegary et al., 2010). Moreover, the public has raised calls for public participation due to ethical and moral issues caused by the new genetics (Etchegary et al., 2010).

RESEARCH METHOD

The questionnaires were administered by means of face-to-face surveys to all respondents who are directly involved in medical genetics at three government hospitals in the Klang Valley, from June to September 2018. The respondents involved in this study were selected using the stratified random sampling method, based on shared characteristics. The advantage of using this sampling method is that bias can be reduced. In addition, findings can be generalized to the target population (Lund Research Ltd, 2019). The respondents were divided into two stakeholder groups-healthcare providers (n=221) and patients with genetic diseases or members of their family (n=200). The statistical program SPSS for MAC iOS was used to analyse the data in this study. The survey instrument measuring stakeholders' intention to adopt GT applications and its predicting factors was designed on the basis of past studies (Gaskell et al., 2003; Amin et al., 2007, 2014, 2017&2018). The instrument's validity (face and content) was examined by five experts in the areas of consumer behaviour, perception studies, acceptance of new technologies, ethical issues in gene technology, and measurement. Based on the comments given by the experts, each item in the constructs were revised and validated by certified translators (using back translation). The survey answers were scored using a seven-point Likert scale. The questionnaire was presented in two languages; Malay and English.

RESULTS AND DISCUSSIONS

Table 1 shows the overall results of the Malaysian stakeholders' intentions and its predictors with regard to adopting GT application. From the results, it is clear that Malaysian stakeholders demonstrate a strong intention to adopt GT (with a mean score of 5.55). They also expressed a have high level of trust in key players involved directly in medical genetics (with a mean score of 5.31) and claimed the application can be accepted on religious grounds (with a mean score of 5.40). These might be due to the fact that all respondents are directly involved in the provision of medical genetics services, and have a good knowledge as well as good engagement with regard to medical genetics. Moreover, previous studies also reported that the trust factor and religious acceptance act as a determinant of the acceptance of gene

technology (Amin et al., 2018). On the other hand, the Malaysian stakeholders also agreed that GT offers high benefits (with a mean score of 5.50) but, at the same time, they perceived the test as having moderate risks and having moderate issues with regard to GT (with a mean score of 3.57 and 4.28, respectively). A possible explanation for this might be that Malaysian stakeholders are remain concerned about their potential risks of GT such as genetic discrimination, higher insurance rates and getting a job. The results of this study are in line with those of previous studies which reported that respondents are generally interested and show positive attitudes with regard to GT (Gaskell et al., 2003; Henneman et al., 2004; Etchegary et al., 2010; Haga et al., 2013; Salm et al., 2014). Although they expressed high intentions to make use of the applications, they also expressed concerns on the associated risks such as genetic discrimination, privacy issues associated with genetic information which could have implications for insurance policies or job security (Apse et al., 2004; Fulda & Lykens, 2006), and ethical and moral issues (Lippman, 1999). The successful acceptance of GT and how issues of public concern are dealt with are considered important determinants of future success in terms of this application.

Table 1
INTENTIONS TO ADOPT GENETIC TESTING

Factors	Mean Score ± Standard Deviation	Interpretation
Engagement	5.05 ± 1.49	Moderate*
Trust in Key Players	5.31 ± 0.94	High
Perceived Benefits	5.50 ± 1.06	High
Perceived Risks	3.57 ± 1.27	Moderate
Religious Acceptance	5.40 ± 1.26	High
Issues of Concern with regard to GT	4.28 ± 1.37	Moderate
Intention to Adopt GT	5.55 ± 1.21	High

Note: 1-2.99: Low; 3.00-5.00: Moderate; 5.01 – 7.00: High*: 0-3.33: Low; 3.34-6.66: Moderate; 6.67- 10: High

CONCLUSION

This paper has provided an insight with regard to identifying Malaysian stakeholders' intention and its predictors to adopt GT. Genetic testing may bring potential benefits to society and the results may be useful in terms of informing people when it comes to making decisions with regard to managing their healthcare. However, more research is needed to identify and overcome the issues of public concern for the successful development and implementation of GT in Malaysia.

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REFERENCES

Ahram, M., Othman, A., Shahrouri, M., & Mustafa, E. (2014). Factors influencing public participation in biobanking. *European Journal of Human Genetics*, *22*(4), 445.

Allum, N., Sibley, E., Sturgis, P., & Stoneman, P. (2014). Religious beliefs, knowledge about science and attitudes towards medical genetics. *Public Understanding of Science*, *23*(7), 833-849.

Amin, L., Azad, M.A.K., Ahmad Azlan, N.A., & Zulkifli, F. (2014). Factors influencing stakeholders' attitudes toward cross-kingdom gene transfer in rice. *New Genetics and Society*, *33*(4), 370-399

Amin, L., Hashim, H., Mahadi, Z., & Ismail, K. (2018). Determinants of the willingness to participate in biobanking among Malaysian stakeholders in the Klang Valley. *BMC Medical Research Methodology*, *18*(1), 163.

Amin, L., Hashim, H., Mahadi, Z., Ibrahim, M., & Ismail, K. (2017). Determinants of stakeholders' attitudes towards biodiesel. *Biotechnology for Biofuels*, *10*(1), 219.

Amin, L., Jahi, J. M., Nor, A. R. M., Osman, M., & Mahadi, N. M. (2007). Public acceptance of modern biotechnology. *Asia Pacific Journal of Molecular Biology & Biotechnology*, *15*(2), 39-51.

Apse, K.A., Biesecker, B.B., Giardiello, F.M., Fuller, B.P., & Bernhardt, B.A. (2004). Perceptions of genetic discrimination among at-risk relatives of colorectal cancer patients. *Genetics in medicine: official journal of the American College of Medical Genetics*, *6*(6), 510-516.

Chokoshvili, D., Belmans, C., Poncelet, R., Sanders, S., Vaes, D., Vears, D., Janssens, S., Huys, I., Borry, P. (2017). Public views on genetics and genetic testing: a survey of the general public in Belgium. *Genetic testing and molecular biomarkers*, *21*(3), 195-201.

Etchegary, H., Cappelli, M., Potter, B., Vloet, M., Graham, I., Walker, M., & Wilson, B. (2010). Attitude and knowledge about genetics and genetic testing. *Public Health Genomics*, *13*(2), 80-88.

Frewer, L. J. (2017). Consumer acceptance and rejection of emerging agrifood technologies and their applications. *European Review of Agricultural Economics*, *44*(4), 683-704.

Fulda, K.G., & Lykens, K. (2006). Ethical issues in predictive genetic testing: a public health perspective. *Journal of Medical Ethics*, *32*(3), 143-147.

Gaskell, G., Allum, N., & Stares, S. (2003). Europeans and biotechnology in 2002: Eurobarometer 58.0. *Brussels: European Commission*.

Giles, E.L., Kuznesof, S., Clark, B., Hubbard, C., & Frewer, L.J. (2015). Consumer acceptance of and willingness to pay for food nanotechnology: a systematic review. *Journal of Nanoparticle Research*, *17*(12), 467.

Gottweis, H. (2002). Gene therapy and the public: a matter of trust. *Gene Therapy*, *9*(11), 667.

Haga, S.B., Barry, W.T., Mills, R., Ginsburg, G.S., Svetkey, L., Sullivan, J., & Willard, H.F. (2013). Public knowledge of and attitudes toward genetics and genetic testing. *Genetic Testing and Molecular Biomarkers*, *17*(4), 327-335.

Henneman, L., Timmermans, D.R., & Van der Wal, G. (2004). Public experiences, knowledge and expectations about medical genetics and the use of genetic information. *Public Health Genomics*, *7*(1), 33-43.

Ji, Y., Si, Y., McMillin, G.A., & Lyon, E. (2018). Clinical pharmacogenomics testing in the era of next generation sequencing: challenges and opportunities for precision medicine. *Expert Review of Molecular Diagnostics*, *18*(5), 411-421.

Katz-Kimchi, M., Martin, K., Weber, V., & Taylor, K. (2011). Gauging public engagement with science and technology issues. *Poroi*, *7*(1), 10.

Lee, J.M.H., & Thong, M.K. (2013). Genetic counseling services and development of training programs in Malaysia. *Journal of genetic counseling*, *22*(6), 911-916.

Lippman, A. (1999). Embodied knowledge and making sense of prenatal diagnosis. *Journal of genetic counseling*, *8*(5), 255-274.

Lund Research Ltd (n.d.). Retrieved July 9, 2019, from http://dissertation.laerd.com/stratified-random-sampling.php

Motulsky, A.G., Holtzman, N.A., Fullarton, J.E., & Andrews, L.B. (1994). *Assessing genetic risks: implications for health and social policy*. National Academies Press.

Mustapa, M.A.C., Amin, L., & Razman, M.R. (2019). Behavioural Intention to Adopt Pharmacogenomics and its Predicting Factors in Malaysia. *Academy of Strategic Management Journal*.

Pin, R.R. (2009). *Perceptions of nutrigenomics: affect, cognition & behavioural intention*.

Salleh, H.S., Noor, A.M., Mat, N.H.N., Yusof, Y., & Mohamed, W.N. (2015). Consumer-behavioural intention towards the consumption of functional food in Malaysia: Their profiles and behaviours. *International Business & Economics Research Journal (IBER)*, *14*(4), 727-734.

Salm, M., Abbate, K., Appelbaum, P., Ottman, R., Chung, W., Marder, K., Leu, C.S., Alcalay, R., Goldman, J., Curtis, A.M., Leech, C. (2014). Use of genetic tests among neurologists and psychiatrists: knowledge, attitudes, behaviors, and needs for training. *Journal of Genetic Counseling*, *23*(2), 156-163.

Semsarian, C., & Ingles, J. (2017). A clinical approach to genetic testing for non-specialists. *BMJ*, *358*, j4101.

Siegrist, M. (2000). The influence of trust and perceptions of risks and benefits on the acceptance of gene technology. *Risk Analysis*, *20*(2), 195-204.

Sweeny, K., Ghane, A., Legg, A.M., Huynh, H.P., & Andrews, S.E. (2014). Predictors of genetic testing decisions: a systematic review and critique of the literature. *Journal of Genetic Counseling*, *23*(3), 263-288.

White, M.T. (2009). Making sense of genetic uncertainty: the role of religion and spirituality. In *American Journal of Medical Genetics Part C: Seminars in Medical Genetics*. Hoboken: Wiley Subscription Services, Inc., A Wiley Company.