

Stakeholders' Attitudes towards Biobanks in Malaysia

Sikap Pihak Berkepentingan terhadap Biobank di Malaysia

HASRIZUL HASHIM, LATIFAH AMIN, ZURINA MAHADI & KHAIDZIR ISMAIL

ABSTRACT

The Malaysian Cabinet's approval of MyCohort in 2005 was seen as the crucial step toward the country having its very first biobank to improve the prevention, diagnosis and treatment of diseases. Past studies have shown that public attitudes towards biobanking depend heavily upon several factors including public engagement with biobanks, trust in key actors, privacy and data security, perceived benefit, altruism and certain demographic variables. The objective of this paper is to assess and compare the attitude levels of the Malaysian stakeholders' towards the application of biobanks across education levels and religion. A survey was carried out on 509 adult respondents in the Klang Valley region of Malaysia. Results of the study have substantiated that the Malaysian stakeholders' attitudes towards biobank were classified as high. Despite their high levels of perceived benefit and religious acceptance, they also expressed moderately high levels of concern when it comes to issues of data and specimen protection; this suggests that the Malaysian stakeholders also tend to be critical upon expressing their views towards a complex system such as biobanks. One-way MANOVA initially has detected a significant difference of attitude towards biobanks across stakeholder groups, education level and religion. Series of univariate analysis following the MANOVA, as well as Post Hoc analysis, also confirm significant difference of attitude existing across stakeholders; however, no significant differences were detected across education level and religion. The research finding serves as a useful benchmark for scientists and government regulators to understand public attitudes to biobanks before they are set into use.

Keywords: Attitude; biobank; religion; education; Malaysia

ABSTRAK

Kelulusan MyCohort oleh kabinet pada tahun 2005 dilihat sebagai langkah penting negara untuk memiliki Biobanknya yang pertama dalam meningkatkan pencegahan, diagnosis dan rawatan penyakit. Kajian lampau menunjukkan sikap orang ramai terhadap biobank bergantung kepada beberapa faktor antaranya termasuklah penglibatan awam, kepercayaan kepada pemain utama, privasi dan keselamatan data, manfaat yang dijangka, altruisma dan pembolehubah demografik tertentu. Objektif kajian ini adalah untuk menilai dan membandingkan tahap sikap pihak berkepentingan di Malaysia terhadap Biobank berdasarkan tahap pendidikan dan agama. Kajian telah dijalankan ke atas 509 responden dewasa di kawasan Lembah Klang, Malaysia. Hasil kajian mendapati sikap pihak berkepentingan terhadap Biobank boleh diklasifikasikan sebagai tinggi. Walaupun persepsi faedah dan penerimaan agama mereka adalah pada tahap yang tinggi, mereka turut menzahirkan tahap kebimbangan yang sederhana tinggi apabila merujuk kepada isu-isu perlindungan data dan spesimen. Hal ini mencadangkan pihak berkepentingan di Malaysia juga cenderung untuk menjadi kritikal apabila menyuarakan pandangan mereka terhadap sistem yang kompleks seperti Biobank. MANOVA satu hala pada mulanya telah mengesan perbezaan yang signifikan sikap terhadap Biobank berdasarkan kumpulan pihak berkepentingan, tahap pendidikan dan agama. Lanjutan analisis univariat dan analisis Post Hoc mengesahkan bahawa wujud perbezaan sikap secara signifikan merentasi kumpulan pihak berkepentingan, namun tiada perbezaan yang signifikan wujud berdasarkan tahap pendidikan dan agama. Hasil kajian ini boleh dijadikan penanda aras yang bermanfaat kepada para saintis dan badan kerajaan yang terlibat dalam pengawalan untuk memahami sikap masyarakat terhadap biobank sebelum ia dilaksanakan.

Kata kunci: Sikap; biobank; agama; pendidikan; Malaysia

INTRODUCTION

In many countries biobanks are defined as a collection of human biological samples stored and regulated for use in scientific study by connecting the samples to the phenotypic and demographic data of the donor (Organisation for Economic Co-operation and Development 2009, Council of Europe, Committee of Ministers 2006). The main purpose for creating the biobanks is to have this genotype-to-phenotype-relationship database accessible for various research projects aimed at improving the understanding of medical conditions including their diagnosis, prevention and treatment (Gregersen et al. 2015; Henderson et al. 2013, Litton, 2011). With the introduction of biobanks the laborious process in medical research, which involves the donor data and biological sample collection, will be avoided, thus aiding the scientific research to advance swiftly.

The biological samples obtained and maintained by biobanks are usually the residual samples from patients in the course of clinical care. Samples such as serum (plasma) and solid tissue specimens are commonly being stored. Nevertheless, other biobanks also maintain peripheral blood cells or bone marrow, cord blood derivatives, pathological body fluid, cell lines, saliva, urine, stools, hair and toenails (Henderson et al. 2013, Kaufman et al. 2008, National Human Genome Research Institute 2004). Prior to the collection of samples and data, the donors would undergo a baseline interview that includes a few questions regarding their lifestyle, medical history and demographic information (The Malaysian Cohort 2014); whereas, other physical assessments such as height, weight, waist and hip circumference, body fat percentage, bone density, fitness, grip strength, lung function, heart rate, blood pressure, vision and hearing are also being recorded (Hobbs et al. 2012, Kaufman et al. 2008, National Human Genome Research Institute 2004). The process of obtaining these biological samples is done by either opting-in or opting-out schemes. In an opt-in scheme, a person explicitly expresses his or her consent; in an opt out scheme, the subject is assumed to enrol in a biobank after they have obtained healthcare in certain settings (Austin, Harding & McElroy 2003) and inaction is treated as a signal of consent (Beyleveld & Buchanan 2007). Whereas the first method is more acceptable and positively perceived by the public (Mancini et al. 2011), the latter could become an issue, especially when the samples are taken and

used without the donor's knowledge and possibly against their will (Giesbertz, Bredenoord & van Delden 2012).

Other than the issue of public consent, privacy and data protection, and benefit sharing are among other public concerns regarding biobanks and have been critically discussed. Past studies have shown that public attitudes to biobanking depends heavily upon several factors including public engagement with biobanks (Ahram, Othman & Shahrouri 2012, Gaskell et al. 2011, Lemke et al. 2010), trust in key actors (Gaskell et al. 2011; Hansson 2005; Kettis-Lindblad et al. 2006), privacy and data security (Gaskell et al. 2011; Kaufman et al. 2009), perceived benefit, altruism (Gaskell et al. 2011), religious acceptance (Ahram, Othman & Shahrouri 2013; Igbe & Adebamowo 2012; Nasrella & Clark 2012) and demographic variables (Critchley et al. 2010; Kaufman et al. 2009; Goodson & Vernon 2004; McQuillan et al. 2003; Wong et al. 2004b).

Generally, biobanking is widely accepted by the public across the world. It was reported in Sweden that more than three quarters of the surveyed Swedes were willing to donate samples for genetic research (Kettis-Lindblad et al. 2006), while 94% would agree or consider agreeing to donate samples for future research if they were given the option to choose between various methods of consent (Nilstun & Hermeren 2006). Furthermore, more than three quarters of British dental patients would donate excess tissue to cancer research if requested (Goodson & Vernon 2004), while 74% of the Irish surveyed have stated their willingness to donate excess tissue for non-genetic research, as well as endorsing their tissues being stored for future research (Cousins, McGee & Ring 2005). In some Islamic countries the public has positively viewed biobanking, with a majority or two-thirds of the surveyed populations in Jordan (Ahram, Othman & Shahrouri 2012), Saudi Arabia (Al-Jumah & Abolfotouh 2011) and Qatar (Nasrella & Clark 2012) expressing their support. Meanwhile, in Malaysia, there is no such study related to public attitudes to biobanking; however, the closest example can be taken from an eye bank for a transplantation survey using medical students as the target samples. The results of the study suggest there is a need to educate young adults in society, as the majority did not know such banks exists (Bharti et al. 2009). This low level of awareness of medical biotechnology related areas, among the Malaysian public, is not novel as Latifah et al. (2011) also reported that Malaysians'

TABLE 1. Background of the Surveyed Respondents

Background	Frequency	Percentage	Background	Frequency	Percentage
Stakeholder group			Age		
Producers	40	7.9	18-25 years old	181	35.6
Scientists	50	9.8	26-40 years old	231	45.4
Policy makers	32	6.3	≥41 years old	97	19.1
NGOs	36	7.1			
Media	46	9.0	Race		
University students	41	8.1	Malay	275	54.0
Islamic scholars	34	6.7	Chinese	111	21.8
Buddhist scholars	33	6.5	Indian	97	19.1
Christian scholars	31	6.1	Sabah natives	8	1.6
Hindu scholars	36	7.1	Sarawak natives	9	1.8
Consumers	130	25.5	Others	9	1.8
Gender			Religion		
Male	244	47.9	Muslim	290	57.0
Female	265	52.1	Buddhist	85	16.7
Education level			Hindus	73	14.3
Secondary schools	77	15.1	Christian	58	11.2
Diploma/pre-university	111	21.8	Others	3	0.8
University	318	62.5			
Others	3	0.6			

awareness, knowledge and engagement with modern biotechnology were on a the moderate level.

The objective of this paper is to assess and compare the attitudes of the Klang Valley stakeholders towards biobanking across their education level and religion. The first biobank in Malaysia, known as “The Malaysian Cohort” or MyCohort, was initiated by the Prime Minister, Tun Dato’ Sri Haji Abdullah bin Haji Ahmad in 2004 and approved by the cabinet in the following year. With the establishment of the biobank and its on-going recruitment for participants, this study aims to assess the current level of public engagement and attitudes towards the application and to discuss the matter thoroughly, hence, in turn, the findings could guide its development in Malaysia.

MATERIALS AND METHOD

SURVEY DATA COLLECTION

The research data was collected by a survey of 509 adult respondents (above 18 years old) in the Klang Valley region of Malaysia. The respondents were stratified according to the stakeholders’ groups, which directly or indirectly related to modern

biotechnology development in Malaysia; they were chosen using a stratified purposive sampling technique. The corresponding stakeholders’ groups were as follows: producers (industry), policy makers, scientists, NGOs, media, university students, religious scholars (Muslim, Christian, Hindu and Buddhist), and consumers (Table 1). Taking into account that this study was quantitative in nature, the minimum sample size required for each statistical analysis was considered. Comparison of attitude across education levels (three groups) and religions (four groups) were carried out using one-way Multivariate Analysis of Variance (MANOVA). In order to have a medium effect size ($f=0.25$) at $p=0.05$, $u=2$, a sample of 52 subjects per education level group is required to obtain a power of 0.80, whereas, a sample of 44 subjects per group is required for the religion category ($f=0.25$ at $p=0.05$, $u=3$) (Cohen 1969).

A set of questionnaires was distributed during data collection to the respondents by a group of trained enumerators. A brief introduction regarding modern biotechnology and its application, including the purpose of biobanking, were also presented to the respondents prior to the questionnaire. In addition, respondents were also allowed to ask a few questions to give them some overview of the study and to ensure they understood the risks and benefits related to biobanking application.

INSTRUMENT

The multi-dimensional instrument measuring attitudes towards biobanking in this study was constructed based on earlier work (Latifah et al. 2011, 2013). The instrument included six dimensions of attitude towards biobanking consisting of the four dimensions used by the Eurobarometer surveys (Gaskell et al. 2000, Gaskell, Allum &

Stares 2003): perceived benefits, perceived risks, perceived moral concerns, and encouragement with the two additional dimensions of issues of data and specimen protection (Gaskell et al. 2010) and religious acceptance (Kelley 1995, Nicholas 2000). The items listed in Table 2 were measured in 7-point likert scales from the lowest to the highest level of agreement.

TABLE 2. Measurement Scales and Reliability

Factor	Items	Standardized factor loading	Corrected item-total correlated	α
Perceived Benefits	Enhance quality of life	0.61	0.54	0.75
	Future research will deal with existing dangers	0.53	0.41	
	Ought be regulated by the government	0.66	0.50	
	Solve problems that cannot be solved by traditional methods	0.79	0.55	
	Benefits exceed risks	0.71	0.60	
Perceived Risks	Feeling of anxiety	0.64	0.62	0.86
	Long-term effects	0.76	0.66	
	Pose threat to future generations	0.77	0.71	
	May give rise to unknown consequences	0.71	0.57	
	Catastrophic potential	0.77	0.69	
	Overall risk magnitude	0.81	0.65	
Perceived Moral Concerns	Over the limit	0.74	0.70	0.81
	“Playing god”	0.82	0.66	
	Reduce the status of living things to machines	0.72	0.63	
Issues of data and specimen protection	Ownership issue	0.83	0.45	0.62
	Misuse of data and specimen by researchers	0.75	0.45	
Religious Acceptance	Accepted by religion	0.83	0.72	0.83
	Accepted by customs	0.77	0.72	
Encouragement	Intensive research	0.81	0.66	0.87
	should be encouraged			
	Should be commercialized	0.78	0.72	
	Should be given monetary support by the government	0.82	0.77	
	Overall encouragement	0.79	0.66	
	Government’s responsibility to ensure it is beneficial	0.72	0.70	

DATA ANALYSIS

Reliability (Cronbach's alpha) tests were carried out using SPSS version 20.0 to evaluate the consistency and uni-dimensionality of the constructs. Discrete statistics, utilizing mean scores and standard deviation of each factor, were computed, while one-way MANOVA were also carried out using the same statistical package.

VALIDITY

Validity measure was assessed by the factor loadings. The standardized loadings of all factors were greater than 0.5 indicating a good validity, as suggested by Hair et al. (1992, 2010) (Table 2).

RELIABILITY

There are two reliabilities measured in this paper: internal consistency (Cronbach's alpha) and corrected item-total correlation reliability. The Cronbach's alpha coefficients for all of the constructs in this study were considered good (above 0.60) (Table 2). The corrected item-total correlations for all items in each dimension were also considered good (correlation coefficients greater than 0.4) (Table 2).

RESULTS

Attitudes towards biobanking were analysed based on six dimensions: Perceived benefits, perceived risks, perceived moral concerns, issues of data and specimen protection, religious acceptance, and encouragement. Following MANOVA, the univariate ANOVA's with Bonferroni correction ($\alpha = 0.0083$) was applied in order to circumvent the inflation of Type I errors (Tabachnick & Fidell 2001).

PERCEIVED BENEFITS

Overall, the Malaysian perception of benefit regarding biobanks was in the moderate range with its mean score above the mid-point of 4.0 (mean score of 4.60) (Table 7). The scientists and university students saw high benefits in biobanking,

whereas other stakeholder groups tended to see it as moderate (Table 5). Respondents who hold a tertiary education level were shown to have the highest level of perceived benefits towards biobanking (mean score of 4.70) compared to other education levels; whereas, respondents who possess a pre-university education rated it lowest (mean score of 4.42) (Table 7). Meanwhile, Christians have been shown to have the highest level of perceived benefits towards biobanking (mean score of 4.72), whereas Hindus rated it at the lowest (mean score of 4.50) (Table 8).

One-way MANOVA was performed to compare the stakeholders' attitudes towards biobanking, as well as to explore the effect of education levels and religion on attitudes to biobanking, respectively. The variance-covariance matrices were found to be not homogenous as Box's $M = 413.247$, $F = 1.846$, $p < .001$ (for the stakeholders' groups), Box's $M = 123.583$, $F = 2.869$, $p < .001$ (for education levels) and Box's $M = 109.412$, $F = 1.681$, $p < .001$ (for religion) (Table 3); hence, Pillai's trace was utilized as recommended by previous researchers (Coakes, 2005; Hair et al., 1998; Pallant, 2001; Tabachnick & Fidell, 2001). One-way MANOVA has detected significant differences of attitude towards biobanking across stakeholders' groups (Pillai's Trace = 0.361, $F = 3.174$, $p < 0.05$) (Table 4). Univariate analysis was also significant for differences of perceived benefit level across stakeholder group ($F = 4.324$, $p < .001$). Post hoc analysis of the beneficial aspects of biobanking highlighted the significant difference in opinion of the scientists and the university students, as compared to the media and Islamic and Hindu scholars (Table 5). The Buddhist scholars' opinions on the beneficial aspects of biobanking also significantly differed from the media and the Islamic scholars (Table 5).

Although one-way MANOVA initially detected significant differences of attitude towards biobanks across education levels and religions (Education level, Pillai's Trace = 0.045, $F = 1.906$, $p < 0.05$; Religion, Pillai's Trace = 0.064, $F = 1.802$, $p < 0.05$) (Table 4), a series of univariate analysis following the MANOVA revealed that both education level and religion do not affect the perceived benefits of biobanks (Tables 9 & 10).

PERCEIVED RISKS

Although weighted below the mid-point of 4.0, the Malaysian risk perception towards biobanks was still considered as moderate (mean score of 3.93) (Table 7). The scientists were shown to have the lowest risk perception on biobanking among all stakeholder groups tested in this study (mean score 3.09) (Table 5). Post hoc analysis also confirmed that their view on the risk aspects of biobanks differed significantly from those of the producers, the NGOs, media, university students, Islamic scholars, Buddhist scholars, Hindu scholars and the consumers (Table 5). Respondents who possess a pre-university education perceived biobanking as having the highest risk (mean score of 4.18), as compared to the remaining two groups of education level (mean score of 3.86) (Table 7). Further univariate analysis has shown that no significant difference has been detected for perceived risk across education levels (Table 9).

Meanwhile, the Christians were shown to perceive biobanks as risky (mean score of 4.15), as compared to the Buddhists, Hindus and Muslims; Muslims were shown to have the lowest level of perceived risk towards biobanks (mean score of 3.84) (Table 8). However, univariate analysis could not detect any significant differences in the risk ratings of biobanks for different religious groups (Table 10).

PERCEIVED MORAL CONCERNS

When confronted with the moral aspects, the stakeholders perceived biobanking as raising moderate moral concerns (overall mean score below the mid-point value of 4.0) (Table 5). The scientists showed the lowest perception of moral concern with biobanks among all stakeholder groups tested in this study (mean score 2.95), whereas the Islamic scholars had the highest moral concerns (mean score 4.45, above the mid-point value of 4.0) (Table 5). Post hoc analysis confirmed that the Islamic scholars' view on the matter differed significantly from those of the producers, scientists, policy makers and the media (Table 5). In addition, the Hindu scholars' concern regarding the moral aspects of biobanks also differed significantly from that of the producers, scientists, media and the consumers (Table 5). Although

ANOVA has detected significant differences in the moral concern over biobanking for different stakeholder groups ($F = 5.384, p < .001$), further univariate analysis, however, could not detect any significant differences in the moral concern related to biobanks across education levels and religions (Tables 9 & 10).

ISSUES OF DATA AND SPECIMEN PROTECTION

When asked about the ownership issue and the probability of misuse of data and specimen by the researchers, regardless their education level, the Malaysian stakeholders expressed their moderate concern on the matter (overall mean score of 4.79) (Table 7). The producers, scientists and Christian scholars showed their high agreement with the issues of data and specimen protection, which post hoc analysis confirmed differed significantly with the media (mean score of 4.16) (Table 6). The Christians were shown to have the highest level of concern regarding issues of data and specimen protection (mean score of 5.22). Meanwhile, the Muslims, Hindus and Buddhists only exhibited moderate levels of concern towards the issue (Table 8). Further univariate analysis, however, confirmed that there are no significant differences for issues of data and specimen protection of biobanks across education levels and religions (Tables 9 & 10).

RELIGIOUS ACCEPTANCE

Overall, the Malaysian stakeholders moderately believed that the application of biobanking could be accepted by their religion and customs (mean score of 4.22) (Table 7). The Buddhist scholars strongly believed that biobanking is acceptable according to their religion and customs (mean score of 4.80, above the mid-point of 4.0), as compared to the media, Islamic scholars, Hindu scholars and consumers (Table 6). Respondents who possess a secondary education scored the highest mean score of religious acceptance (mean score of 4.37), as compared to the remaining two groups of education level (Table 7). On the other hand, the Christians were found to have the lowest mean score of religious acceptance among the four religions tested in this study (mean score below the mid-point value of 4.0) (Table 8). Although considered moderate, the Muslim, Hindu and

Buddhist religious consideration of biobanking application was rated above the mid-point of 4.0 with the highest score belonging to the Buddhists (mean score of 4.28) (Table 8). Level of education and religion, however, does not affect the religious acceptance of biobanking significantly since univariate analysis could not detect any significant differences across the tested variables (Tables 9 & 10).

ENCOURAGEMENT

The overall mean score for encouragement of biobanking by the Malaysian stakeholders was labelled as high (overall mean score of 5.09) (Table 7) with the most supportive groups being the scientists (mean score of 5.60), Buddhist scholars (mean score of 5.50) and the university students (mean score of 5.45). The encouragement shown by these groups towards biobanks was confirmed

by post hoc analysis to differ significantly with the media (mean score of 4.69) and the Islamic scholars (mean score of 4.61) (Table 6). On the other hand, the most supportive groups, according to education level and religion, were found to be those who possess a tertiary education (mean score of 5.20) (Table 7) and the Buddhists (mean score of 5.24, Table 8). Both secondary and pre-university education groups showed moderate encouragement towards biobanks (mean score above the mid-point value of 4.0) (Table 7). Meanwhile, the Christians and Muslims were also found to exhibit high support towards biobanks, whereas the Hindus showed only moderate support towards its application (Table 8). Despite the difference of interpretation for the mean scores of all groups, univariate analysis, however, could not detect any significant differences in encouragement of biobanks across education levels and religions (Tables 9 & 10).

TABLE 3. Box's M Test to Determine the Homogeneity of Variance-Covariance within the Attitude Variable Across Stakeholders, Education Level and Religion

Category	Box's M	F	DF 1	DF 2	Sig.
Stakeholders	413.247	1.846	210	124457.826	0.000
Education level	123.583	2.869	42	171359.457	0.000
Religion	109.412	1.681	63	146619.536	0.002

*p<0.05

TABLE 4. One-way MANOVA to Determine Attitude towards Biobanks across Stakeholders, Education Level and Religion

Effect	Pillai's Trace	F	DF.h	DF.e	Sig.
Stakeholders	0.361	3.174	60	2976	0.000*
Education Level	0.045	1.906	12	994	0.030*
Religion	0.064	1.802	18	1491	0.020*

*p<0.05

TABLE 5. Mean Scores, Standard Deviation and Post Hoc Test Results for Perceived Benefits, Perceived Risk and Perceived Moral Concerns of Biobanks across Stakeholder Group

Stakeholders	Mean score \pm Std dev.* and Interpretation**					
	Perceived benefits		Perceived risks		Perceived moral concerns	
1. Producers	4.68 \pm 0.80	Moderate	3.95 \pm 0.96	Moderate	3.23 \pm 1.10	Moderate
2. Scientists	5.07 \pm 1.14 ^{5,7,10}	High	3.09 \pm 1.15 ^{1,4,5,6,7,8,10,11}	Moderate	2.95 \pm 1.24	Low
3. Policy Makers	4.85 \pm 1.20	Moderate	3.66 \pm 1.15	Moderate	3.17 \pm 1.50	Moderate
4. NGOs	4.48 \pm 0.81	Moderate	4.14 \pm 0.81	Moderate	3.82 \pm 0.90 ²	Moderate
5. Media	4.20 \pm 0.77	Moderate	3.79 \pm 0.73 ⁷	Moderate	3.48 \pm 0.91	Moderate
6. University Students	5.06 \pm 1.01 ^{5,7,10}	High	3.99 \pm 1.29	Moderate	3.74 \pm 1.19	Moderate
7. Islamic Scholars	4.15 \pm 0.72	Moderate	4.42 \pm 0.76	Moderate	4.45 \pm 1.03 ^{1,2,3,5}	Moderate
8. Buddhist Scholars	4.76 \pm 0.59 ^{5,7}	Moderate	4.31 \pm 0.70	Moderate	3.88 \pm 1.25	Moderate
9. Christian Scholars	4.65 \pm 1.04	Moderate	3.88 \pm 1.09	Moderate	3.97 \pm 1.51	Moderate
10. Hindu Scholars	4.30 \pm 0.85	Moderate	4.31 \pm 0.88	Moderate	4.16 \pm 0.90 ^{1,2,5,11}	Moderate
11. Consumers	4.52 \pm 1.15	Moderate	3.96 \pm 1.13	Moderate	3.45 \pm 1.40	Moderate
Overall (n = 509)	4.60 \pm 1.01	Moderate	3.93 \pm 1.07	Moderate	3.60 \pm 1.28	Moderate

* Post hoc test results showing significant differences of at least $p < 0.05$ between the indicated stakeholder groups, numbered in superscript. Games-Howell's test was carried out to compare perceived benefits, perceived risks and perceived moral concerns across the indicated stakeholder groups.

* Code of stakeholders: ¹Producers, ²Scientists, ³Policy Makers, ⁴NGOs, ⁵Media, ⁶University Students, ⁷Islamic Scholars, ⁸Buddhist Scholars, ⁹Christian Scholars, ¹⁰Hindu scholars, ¹¹Consumers.

** 1.00- 2.99, Low; 3.00-5.00, Moderate; 5.01-7.00, High.

TABLE 6. Mean scores, standard deviation and post hoc test results for issues of data and specimen protection, religious acceptance and encouragement of biobanks across stakeholder groups

Stakeholders	Mean score \pm Std dev.* and Interpretation**					
	Issues of data/specimen protection		Religious acceptance		Encouragement	
1. Producers	5.17 \pm 1.24	High	4.23 \pm 1.07	Moderate	5.41 \pm 1.13	High
2. Scientists	5.01 \pm 1.44	High	4.76 \pm 1.38	Moderate	5.60 \pm 1.06 ^{4,5,7}	High
3. Policy Makers	4.92 \pm 1.22	Moderate	4.24 \pm 1.43	Moderate	5.25 \pm 1.20	High
4. NGOs	4.71 \pm 0.87	Moderate	3.94 \pm 1.35	Moderate	4.67 \pm 1.17	Moderate
5. Media	4.16 \pm 0.98 ^{1,2,9,11}	Moderate	4.00 \pm 1.00	Moderate	4.69 \pm 0.99	Moderate
6. University Students	4.79 \pm 1.34	Moderate	4.37 \pm 1.34	Moderate	5.45 \pm 1.01 ^{5,7}	High
7. Islamic Scholars	4.59 \pm 0.89	Moderate	3.93 \pm 1.21	Moderate	4.61 \pm 1.07	Moderate
8. Buddhist Scholars	4.47 \pm 0.84	Moderate	4.80 \pm 0.75 ^{5,7,10,11}	Moderate	5.50 \pm 0.68 ^{4,5,7}	High
9. Christian Scholars	5.29 \pm 1.27	High	4.37 \pm 1.45	Moderate	5.03 \pm 1.14	High
10. Hindu Scholars	4.54 \pm 1.02	Moderate	3.94 \pm 1.17	Moderate	4.83 \pm 1.13	Moderate
11. Consumers	4.90 \pm 1.19	Moderate	4.07 \pm 1.29	Moderate	5.02 \pm 1.26	High
Overall (n = 509)	4.79 \pm 1.18	Moderate	4.22 \pm 1.27	Moderate	5.09 \pm 1.16	High

* Post hoc test results showing significant differences of at least $p < 0.05$ between the indicated stakeholder groups, numbered in superscript. Games-Howell's test was carried out to compare issues of data and specimen protection, religious acceptance and encouragement across the indicated stakeholder groups.

* Code of stakeholders: ¹Producers, ²Scientists, ³Policy Makers, ⁴NGOs, ⁵Media, ⁶University Students, ⁷Islamic Scholars, ⁸Buddhist Scholars, ⁹Christian Scholars, ¹⁰Hindu scholars, ¹¹Consumers.

** 1.00- 2.99, Low; 3.00-5.00, Moderate; 5.01-7.00, High.

TABLE 7. Mean scores and standard deviation of attitudes towards biobanks across educational level

Attitude dimension	Secondary schools		Diploma/pre-university		University		Overall	
	Mean score \pm Std dev	Interpret.*	Mean score \pm Std dev	Interpret.*	Mean score \pm Std dev	Interpret.*	Mean score \pm Std dev	Interpret.*
Perceived benefits	4.43 \pm 1.01	Moderate	4.42 \pm 1.00	Moderate	4.70 \pm 1.01	Moderate	4.60 \pm 1.01	Moderate
Perceived risks	3.86 \pm 0.87	Moderate	4.18 \pm 1.13	Moderate	3.86 \pm 1.08	Moderate	3.93 \pm 1.07	Moderate
Perceived moral concerns	3.66 \pm 1.25	Moderate	3.85 \pm 1.28	Moderate	3.50 \pm 1.28	Moderate	3.60 \pm 1.28	Moderate
Issues of data & specimen protection	4.80 \pm 0.94	Moderate	4.79 \pm 1.29	Moderate	4.80 \pm 1.20	Moderate	4.79 \pm 1.18	Moderate
Religious acceptance	4.37 \pm 1.03	Moderate	3.90 \pm 1.29	Moderate	4.29 \pm 1.30	Moderate	4.22 \pm 1.27	Moderate
Encouragement	4.97 \pm 1.17	Moderate	4.87 \pm 1.21	Moderate	5.20 \pm 1.12	High	5.09 \pm 1.16	High

*1.00- 2.99, Low; 3.00-5.00, Moderate; 5.01-7.00, High.

TABLE 8. Mean scores and standard deviation of attitudes towards biobanks across religion

Attitude dimension	Muslim		Buddhist		Hindu		Christian	
	Mean score \pm Std dev	Interpret.*	Mean score \pm Std dev	Interpret.*	Mean score \pm Std dev	Interpret.*	Mean score \pm Std dev	Interpret.*
Perceived benefits	4.62 \pm 1.03	Moderate	4.56 \pm 0.84	Moderate	4.50 \pm 1.15	Moderate	4.72 \pm 1.01	Moderate
Perceived risks	3.84 \pm 1.08	Moderate	4.09 \pm 0.89	Moderate	3.93 \pm 1.06	Moderate	4.15 \pm 1.21	Moderate
Perceived moral concerns	3.48 \pm 1.28	Moderate	3.61 \pm 1.11	Moderate	3.82 \pm 1.25	Moderate	3.88 \pm 1.44	Moderate
Issues of data & specimen protection	4.79 \pm 1.16	Moderate	4.60 \pm 1.03	Moderate	4.75 \pm 1.28	Moderate	5.22 \pm 1.26	High
Religious acceptance	4.26 \pm 1.25	Moderate	4.28 \pm 1.07	Moderate	4.21 \pm 1.34	Moderate	3.98 \pm 1.50	Moderate
Encouragement	5.08 \pm 1.14	High	5.24 \pm 1.07	High	4.89 \pm 1.13	Moderate	5.21 \pm 1.13	High

*1.00- 2.99, Low; 3.00-5.00, Moderate; 5.01-7.00, High.

TABLE 9. Univariate one-way ANOVA of attitudes towards biobanks across education level

Dependent Variable	Main Effect	Type III Sum of Squares	D.F	Mean Square	F	Sig.
Perceived Benefits	Education Level	9.136	2	4.568	4.474	0.012
	Error	511.532	501	1.021		
	Total	520.669	503			
Perceived Risks	Education Level	8.773	2	4.386	3.894	0.021
	Error	564.405	501	1.127		
	Total	573.177	503			
Issue of Data and Specimen Protection	Education Level	.017	2	.008	0.006	0.994
	Error	706.188	501	1.410		
	Total	706.205	503			
Perceived Moral Concerns	Education Level	10.457	2	5.229	3.211	0.041
	Error	815.797	501	1.628		
	Total	826.255	503			
Religious Acceptance	Education Level	14.762	2	7.381	4.655	0.010
	Error	794.320	501	1.585		
	Total	809.082	503			
Encouragement	Education Level	9.945	2	4.972	3.768	0.024
	Error	661.094	501	1.320		
	Total	671.039	503			

*p<0.0083

TABLE 10. Univariate one-way ANOVA of attitudes towards biobanks across religion

Dependent Variable	Main Effect	Type III Sum of Squares	D.F	Mean Square	F	Sig.
Perceived Benefits	Religion	1.874	3	0.625	0.604	0.613
	Error	517.388	500	1.035		
	Total	519.262	503			
Perceived Risks	Religion	7.568	3	2.523	2.241	0.083
	Error	562.922	500	1.126		
	Total	570.490	503			
Issue of Data and Specimen Protection	Religion	14.059	3	4.686	3.424	0.017
	Error	684.303	500	1.369		
	Total	698.362	503			
Perceived Moral Concerns	Religion	12.359	3	4.120	2.556	0.055
	Error	805.869	500	1.612		
	Total	818.228	503			
Religious Acceptance	Religion	3.934	3	1.311	0.818	0.484
	Error	801.303	500	1.603		
	Total	805.237	503			
Encouragement	Religion	5.743	3	1.914	1.433	0.232
	Error	667.977	500	1.336		
	Total	673.720	503			

*p<0.0083

DISCUSSION

This study reveals that the acceptance of biobanks by the Malaysian stakeholders varies according to intricate relationships between the attitude dimensions, rather than the demographic variables themselves, namely, education levels and religion. Although the study has not emphasized the interrelationship of the factors in detail, through in-depth regression analysis such as the structural equation modelling, the causal of each factor can be observed and compared with previous studies. For example, the overall mean score of perceived benefits (4.60) in this study is far higher than perceived risks (3.93) and perceived moral concerns (3.60). This finding is consistent throughout all tested groups of education level and religion (Tables 7 & 8); this suggests that the Malaysian stakeholders in the Klang Valley viewed biobanks as less risky and as having fewer moral issues; thus, in turn, they have perceived its promises as far higher. What is more, this result is also congruous with those of previous findings, which suggests that an inverse relationship exists between the perceived benefits and perceived risks of biotechnology products and applications (Latifah et al. 2011, 2015, Gaskell et al. 2000, Pardo, Midden & Miller 2002).

The Malaysian stakeholders in the Klang Valley also believed that biobanking will confront less resistance from a religious point of view; therefore, it will be moderately accepted by their religion and customs (mean score of 4.22) (Table 7). This foundation is strengthened by previous studies, whereby the public gave their support to biobanks and sample donation if they found the application met with little resistance from their religions, regardless of their religiosity and moral beliefs (Ahram, Othman & Shahrouri 2013, Igbe & Adebamowo 2012, Nasrella & Clark 2012). Furthermore, it is also interesting to note that the higher mean score of perceived benefit and religious acceptance (above the mid-point value of 4.0), compared with perceived risks and perceived moral concern, as demonstrated in this study, could be a key to high public support towards biobanking (mean score of 5.09) (Table 7). When biobanking was perceived as beneficial, less risky, raising fewer moral issues and acceptable by religion, the risk associated with it would be highly compensated; consequently, the application would be strongly encouraged. Latifah et al. (2011, 2008) previously

explained this intricate balancing relationship of the attitudinal factors. Moreover, this deduction is also supported by some earlier studies on public perception of modern biotechnology and GM foods. For instance, data from the fourth Eurobarometer survey suggested that perceived benefit was found to be a precondition for Europeans' support of biotechnology applications (Connor & Siegrist 2013, Gaskell et al. 2000, 2006) while the moral aspects of GM applications appeared to act as a veto (Gaskell 2000, Knight 2007).

Although the intricate association of perceived benefits, perceived risks, perceived moral concern, religious acceptance and encouragement has been clearly justified, at some point the Malaysian stakeholders tend to be critical upon expressing their views on the complex technology of biorepository systems such as biobanks. This has been well observed in this study; in spite of the fact that Malaysian stakeholders expressed higher mean scores of perceived benefits and religious acceptance, they also expressed moderately higher concern when it comes to issues of data and specimen protection (overall mean score of 4.79) (Table 7). This scenario is well anticipated as previous studies have demonstrated that the public's unconditional support towards biobanking may exist in a certain way. In both the UK and Germany, biobanks were perceived as beneficial to society; however, willingness to take part in biobanking was conditional on personal privacy risks and the unintended consequences of biobank research, such as discrimination and unethical practices, have been seen as the greatest concerns (Hobbs et al. 2012). Moreover, despite having viewed the application as beneficial to improving human health, Nigerians were also concerned about the issue of confidentiality during biobanking, recognizing that personal information is sensitive and inadvertent release can cause harm (Igbe & Adebamowo 2012). However, the raised concern did not hamper their acceptance of biobanks as they still agreed to share their specimens with other researchers, providing that the prevention of unethical research is guaranteed and that those running the biobank are ethical, trustworthy and competent (Igbe & Adebamowo 2012). In addition, public acceptance and willingness to participate in biobanking can also be strengthened further by the media disseminating the information and issues related to biobanking; this is because previous studies have suggested the role of the media in

augmenting public awareness of various issues (Jamilah et al. 2011, Longstaff & Secko 2010, Nisbet & Fahy 2013).

Comparing across stakeholders, scientists were shown to be the most enthusiastic and optimistic about biobanking and they viewed the application positively. Having a high significant difference in opinion on the beneficial aspects of biobanking clearly makes them perceive the lowest risk and moral concerns about biobanks, as compared to other stakeholders; thus, this makes them as the most supportive group towards the application (Tables 5 & 6). This finding is not surprising as scientists, as we know, have been involved directly with the development of modern biotechnology, as well as the progress of genetic research in the country; therefore, any means of improving the research, such as through the establishment of biobanks, will definitely be seen as a positive sign. The result is substantiated with the previous finding of Aerni and Rieder (2000), which suggests that scientists have a positive perception towards modern biotechnology application as compared to government agencies. Gaskell et al. (2010) also found that those who have a strong foundation in science will be more optimistic towards science and technology and are more inclined to express a positive view on the application.

Meanwhile, the university students also saw the high benefits of biobanks, as compared to the media, the Islamic scholars, and the Hindu scholars (Table 5). They were also very supportive towards the application, as compared to the media and the Islamic scholars (Table 6). This could be due to the fact that those who were majoring in the sciences such as biology, biotechnology, bioscience etc., were still studying; therefore, they were actively seeking information related to modern biotechnology, which could have shaped their positive view towards the application. Therefore, it is much anticipated that they would have been highly optimistic about the potential of biobanks. On the other hand, the Buddhist scholars have emerged as the most optimistic group towards the application of biobanks among the religious scholars tested in this study. Besides the scientists and the university students, the Buddhist scholars' opinion on the beneficial aspects of biobanking also significantly differed with the media and the Islamic scholars (Table 5). The Buddhists scholars also strongly believed that biobanking is acceptable according to their religion, as compared

to the media, Islamic scholars, Hindu scholars and consumers (Table 6); this later explained their high support towards the application (Table 6). The presented result, however, differs from that reported by Noor Ayuni (2010) and Latifah et al. (2013), where the Buddhist scholars had previously expressed slight moral concern as well as giving a moderate encouragement to modern biotechnology applications; a current result could indicate a dramatic change of opinion towards modern biotechnology applications in the past five years. The Islamic scholars, on the other hand, were found to be less optimistic towards the application; they view the application as raising moral concerns, as compared to other groups, whereas, at the same time, they expressed the lowest rating for religious acceptance of biobanking (mean score below the mid-point point value of 4.0). Post hoc analysis confirmed that the Islamic scholars' view on the matter differed significantly from those of the producers, the scientists, the policy makers and the media (Table 5). Besides, the Hindu scholars' concern regarding the moral aspects of biobanking also significantly differed from those of the producers, the scientists, the media and the consumers (Table 5). This finding concludes that both Islamic and Hindu scholars were still conservative towards the issue, as compared to the Buddhist scholars.

Although the producers, scientists and the Christian scholars' attitudes were inclined towards the positive side compared to other stakeholders (i.e., high encouragement towards biobanks), they also seemed to reserve some considerations when it comes to issues of data and specimen protection. Post hoc analysis has confirmed that their highly rated opinion regarding the issue of sample ownership and the probability of misuse of samples and data by the researchers has differed significantly with the media (Table 6). It is true that the concern of the matter was generally raised due to the public's distrust in the ability of even the most sophisticated data protection systems. As mentioned by one of the participants in the focus group study in the United Kingdom, "living in a leak society is a big worry, all sorts of systems are supposed to be secure these days and best intentions are guaranteed until they aren't" (Hobbs et al. 2012). Contrarily, concern about biobank research also centres on questions of trust about what might happen when third parties acquire information derived from the research data, either

legitimately or illegitimately (Hansson 2005). However, according to previous studies, people's concern about privacy issues does not necessarily lead to a rejection of biobanks (Gaskell et al. 2011, Kaufman et al. 2009). This is because the focus group participants in both studies expect that the biobanks will offer the best possible protection if the data are abused by the insurances or employers, for example through the implementation of "opting in" consent as well as the role of ethics committees in the joined research.

Finally, this study also demonstrates the obscure possibility of education level and religion in influencing public attitude towards biobanks. Further univariate analysis following Multivariate Analysis of Variance (MANOVA) confirmed that there are no significant differences for perceived benefits, perceived risks, perceived moral concerns, issues of data and specimen protection, religious acceptance, and encouragement towards biobanks across education levels and religions.

CONCLUSION

This study concludes that the Malaysian stakeholders' attitudes towards biobanks are highly positive. Despite the high-perceived benefit and religious acceptance, the Malaysian stakeholders also expressed moderately high concerns regarding the issues of data and specimen protection related to biobanking; this suggests that they also tend to be critical upon expressing their views towards complex systems such as biobanks. However, there were no significant differences of attitudinal variables across education levels and religion, suggesting the obscure possibility of education level and religion in influencing the public attitude towards biobanks. Finally, the research finding is very useful in order to understand the social acceptance of biobanking, which serves as a database of biological specimens and personal data of civilians for future research. However, a more in-depth study needs to be carried out in order to evaluate the reasons for the high level of concern on data and specimen protection, as well as the role of other demographic variables in shaping the public attitude towards biobanks.

ACKNOWLEDGEMENT

The authors would like to thank Universiti Kebangsaan Malaysia for supporting this research under the DLP-2015-004 and STEM-2014-005 grants.

REFERENCES

- Aerni, P. & Rieder, P. 2000. Acceptance of modern biotechnology in developing countries: a case study of the Philippines. *International Journal of Biotechnology* 2 (1/2/3): 115-131.
- Ahram, M., Othman, A., Shahroui, M. 2012. Public support and consent preference for biomedical research and biobanking in Jordan. *European Journal of Human Genetics*: 1-4. doi:10.1038/ejhg.2012.213.
- Ahram, M., Othman, A., Shahroui, M., Mustafa, E. 2013. Factors influencing public participation in biobanking. *European Journal of Human Genetics*: 1-7.
- Al-Jumah, M. A. & Abolfotouh, M. A. 2011. Public Perception and Attitude of Saudis Toward Organ and Tissue Donation. *Biopreservation and Biobanking* 9(1): 21-27. doi:10.1089/bio.2010.0025.
- Austin, M. A., Harding, S. & McElroy, C. 2003. Genebanks: A Comparison of Eight Proposed International Genetic Databases. *Community genetics* (6)1: 37-45.
- Beylveled, D. & Buchanan, J. A. 2007. *Consent in the law*. Oxford and Portland, Oregon: Hart publishing. pp. 187-227.
- Bharti, M. K., Reddy, S. C., Tajunisah, I. & Ali, N. A. 2009. Awareness and knowledge on eye donation among university students. *Medical Journal of Malaysia* 64(1): 41-5.
- Cohen, J. 1969. *Statistical Power Analysis for the Behavioral Sciences*. New York: Academic Press.
- Connor, M. & Siegrist, M. 2013. Sorting biotechnology applications: results of multi-dimensional scaling (MSD) and cluster analysis. *Public Understanding of Science* 22(2): 128-136.
- Council of Europe, Committee of Ministers. 2006. Recommendation Rec(2006)4 of the Committee of ministers to member states on research on biological materials of human origin.

- Cousins, G., McGee, H., Ring, L., Conroy, R., Kay, E., Croke, D.T., & Tomkin, D. 2005. *Public perceptions of biomedical research: a survey of the general population in Ireland*. Dublin, Health Research Board. Health Services Research Centre, Royal College of Surgeons in Ireland.
- Critchley, C. R., Nicol, D., Otlowski, M. F. A. & Stranger, M. J. A. 2010. Predicting intention to biobank: a national survey. *European Journal of Public Health*: 1–6. doi:10.1093/eurpub/ckq136
- Gaskell, G., Allum, N., Bauer, M., Durant, J., Allansdottir, A., Bonfadelli, H., Boy, D., de Cheveigné, S., Fjaestad, B., Gutteling, J.M., Hampel, J., Jelsøe, E., Jesuino, J.C., Kohring, M., Kronberger, N., Midden, C., Nielsen, T.H., Przystalski, A., Rusanen, T., Sakellaris, G., Torgersen, H., Twardowski, T., Wagner, W. 2000. Biotechnology and the european public. *Nature Biotechnology* (18)9: 935–938.
- Gaskell, G., Allum, N. C., & Stares, S. R. 2003. *Europeans and biotechnology in 2002: Eurobarometer 58.0*. Brussels: European Commission.
- Gaskell, G., Stares, S., Allansdottir, A., Corchero, C. & Jackson, J. 2006. *Europeans and biotechnology in 2005: patterns and trends*. Final Report on Eurobarometer 64.3, Publications Office of the European Union, Luxembourg, 2006.
- Gaskell, G., Stares, S., Allansdottir, A., Allum, N., Castro, P., Esmer, Y., Fischler, C., Jackson, J., Kronberger, N., Hampel, J., Mejlgaard, N., Quintanilha, A., Rammer, A., Revuelta, G., Stoneman, P., Torgersen, H., & Wagner, W. 2010. *Europeans and biotechnology in 2010 Winds of change?*. A report to the European Commission's Directorate-General for Research.
- Gaskell, G., Gottweis, H., Starkbaum, J., Broerse, J. E., Gerber, M., Gottweis, U., Hobbs, A., Ilpo, H., Pashou, M., Snell, K. & Soulier, A. 2011. Publics and Biobanks in Europe: Explaining Heterogeneity. LSG Working Papers 2011/2 – October 5, 2011.
- Giesbertz, N. A. A., Bredenoord, A. L. & van Delden, J. J. M. 2012. Inclusion of Residual Tissue in Biobanks: Opt-In or Opt-Out?. *PLoS Biology* 10(8): e1001373. doi:10.1371/journal.pbio.1001373.
- Goodson, M. L. & Vernon B. G. 2004. A study of public opinion on the use of tissue samples from living subjects for clinical research. *Journal of Clinical Pathology* 57: 135-138.
- Gregersen, P. K., Klein, G., Keogh, M., Kern, M., DeFranco, M., Simpfendorfer, K. R., Kim, S. J., Diamond, B. 2015. The Genotype and Phenotype (GaP) registry: a living biobank for the analysis of quantitative traits. *Immunologic Research* 63(1-3): 107-112.
- Hair, J. F., Anderson, R. E., Tatham, R. L. & Black, W. C. 1992. *Multivariate Data Analysis with Readings*. New York: Macmillan Publishing Company.
- Hair, J. F., Black, W. C., Babin, B. J., & Anderson, R. E. 2010. *Multivariate Data Analysis: A Global Perspective*. New York: Pearson Prentice Hall.
- Hansson M. G. 2005. Building on relationships of trust in biobank research. *Journal of Medical Ethics* 31: 415–418.
- Henderson, G. E., Cadigan, R. J., Edwards, T. P., Conlon, I., Nelson, A. G., Evans, J. P., Davis, A. M., Zimmer, C. & Weiner, B. J. 2013. Characterizing biobank organizations in the U.S.: results from a national survey. *Genome Medicine* 5: 3.
- Hobbs, A., Starkbaum, J., Gottweis, U., Wichmann, H. E. & Gottweis, H. 2012. The Privacy-Reciprocity Connection in Biobanking: Comparing German with UK Strategies. *Public Health Genomics* 15: 272–284.
- Igbe, M. A. & Adebamowo, C. A. 2012. Qualitative study of knowledge and attitudes to biobanking among lay persons in Nigeria. *BMC Medical Ethics* 13: 27
- Jamilah Ahmad, Hasrina Mustafa, Hamidah Abd Hamid & Juliana Abdul Wahab. 2011. Pengetahuan, Sikap dan Amalan Masyarakat Malaysia terhadap Isu Alam Sekitar. *Akademika* 81(3): 103-115.
- Kaufman, D., Geller, G., Leroy, L., Murphy, J., Scott, J., & Hudson, K. 2008. Ethical implications of including children in a large biobank for genetic-epidemiologic research: a qualitative study of public opinion. *American Journal of Medical Genetics. Part C, Seminars in Medical Genetics* 148C(1): 31-9.
- Kaufman, D., Murphy-Bollinger, J., Scott, J. & Hudson, K. 2009. Public Opinion about the Importance of Privacy in Biobank Research. *The American Journal of Human Genetics* 85: 643–654.

- Kelley, J. 1995. Public perceptions of genetic engineering: Australia, 1994. *Final report to the Department of Industry, Science and Technology*, May 1995. http://www.international-survey.org/Kelley_1995_Pub_Percept_Genetic_Engineering2.pdf Retrieved on: 4 May 2012.
- Knight, A. 2007. Intervening effects of knowledge, morality, trust, and benefits on support for animal and plant biotechnology applications. *Risk Analysis* 27(6): 1553–1563.
- Kettis-Lindblad, A., Ring, L., Viberth, E. & Hansson, M. G. 2006. Genetic research and donation of tissue samples to biobanks. What do potential sample donors in the Swedish general public think?. *European Journal of Public Health* 16: 433-440.
- Latifah Amin, Jamil Ahmad, Jamaluddin Md. Jahi, Abd. Rahim Md. Nor, Mohamad Osman & Nor Muhammad Mahadi. 2011. Factors influencing Malaysian public attitudes to agro-biotechnology. *Public Understanding of Science* 20(5): 674-689.
- Latifah Amin, Jamaluddin Md. Jahi & Abd. Rahim Md. Nor. 2013. Stakeholders' Attitude towards genetically modified foods and genetically modified medicine. *Scientific World Journal*. Article ID 516742. <http://dx.doi.org/10.1155/2013/516742>
- Latifah Amin, Md. Abul Kalam Azad, Noor Ayuni Ahmad Azlan & Faizah Zulkifli. 2014. Factors influencing stakeholders' attitude toward cross-kingdom gene transfer in rice. *New Genetics and Society* 33(4): 370-399.
- Latifah Amin & Hasrizul Hashim. 2015. Factors influencing stakeholders attitudes toward genetically modified aedes mosquito. *Science and Engineering Ethics* 21(3): 655-681.
- Lemke, A. A., Wolf, W. A., Hebert-Beirne, J. & Smith, M. E. 2010. Public and Biobank Participant Attitudes toward Genetic Research Participation and Data Sharing. *Public Health Genomics* 13(6): 368–377.
- Litton, J. E. 2011. Biobank informatics: connecting genotypes and phenotypes. *Methods in Molecular Biology* 675: 343-361.
- Longstaff, H. & Secko, D. M. 2010. Media Influence on Biobank Deliberations. *Journal of Health & Mass Communication* 2(1-4): 73-95.
- Mancini, J., Pellegrini, I., Viret, F., Vey, N., Daufresne, L., Chabannon, C. & Julian-Reynier, C. 2011. Consent for Biobanking: Assessing the Understanding and Views of Cancer Patients. *Journal of the National Cancer Institute* 103: 1–4.
- McQuillan, G. M., Porter, K. S., Agelli, M. & Kington, R. 2003. Consent for genetic research in a general population: The NHANES experience. *Genetics in Medicine* 5: 35–42.
- Nasrella, E. & Clark, B. 2012. Public attitudes towards participation in Biobank Qatar. Qatar Foundation Annual Research Forum Proceedings: Vol. 2012, BMP78. DOI: 10.5339/qfarf.2012.BMP78 <http://www.qscience.com/doi/abs/10.5339/qfarf.2012.BMP78?af=R&> Retrieved on: 1 February 2014.
- National Human Genome Research Institute. 2004. Design Considerations for a Potential United States Population-Based Cohort to Determine the Relationships among Genes, Environment, and Health: Recommendations of an Expert Panel. <http://www.genome.gov/Pages/About/OD/ReportsPublications/PotentialUSCohort.pdf> Retrieved on: 8 February 2014.
- Nilstun, T. & Hermeren G. 2006. Human tissue samples and ethics--attitudes of the general public in Sweden to biobank research. *Medicine, Health Care and Philosophy* 9: 81-86.
- Nisbet, M. C. & Fahy, D. 2013. Bioethics in popular science: evaluating the media impact of *The Immortal Life of Henrietta Lacks* on the biobank debate. *BMC Medical Ethics* 14: 10. doi: 10.1186/1472-6939-14-10.
- Noor Ayuni Ahmad Azlan, 2010. Persepsi masyarakat Malaysia terhadap aspek etika tanaman diubah suai genetik: Kajian di Lembah Klang. Tesis Sarjana. Institut Alam Sekitar dan Pembangunan, Universiti Kebangsaan Malaysia.
- Organisation for Economic Co-Operation and Development. 2009. *OECD Guidelines on Human Biobanks And Genetic Research Databases*. Paris: OECD.
- Pardo, R., Midden, C. & Miller, J. D. 2002. Attitude towards biotechnology in the European Union. *Journal of Biotechnology* 98: 9-24.
- Tabachnick, B. G. & Fidell, L. S. 2001. *Using Multivariate Statistics*. 4th edition. Boston: Allyn & Bacon.

The Malaysian Cohort. 2014. Objective. <http://mycohort.gov.my/web/profile/objective.html>
Retrieved on: 20 February 2014.

Wong, M. L., Chia, K. S., Wee, S., Chia, S. E., Lee, J., Koh, W. P., Shen, H. M., Thumboo, J. & Sofjan, D. 2004. Concerns over participation in genetic research among Malay-Muslims, Chinese and Indians in Singapore: a focus group study. *Community Genetics* 7(1): 44–54.

Hasrizul Hashim
Pusat Citra Universiti
Universiti Kebangsaan Malaysia
43600 Selangor
Malaysia
E-mail: ejoy86@gmail.com

Latifah Amin (corresponding author)
Pusat Citra Universiti
Universiti Kebangsaan Malaysia
43600 Selangor
Malaysia
*Institut Islam Hadhari
Universiti Kebangsaan Malaysia
43600 Selangor
Malaysia
Email: nilam@ukm.edu.my

Zurina Mahadi
Pusat Citra Universiti
Universiti Kebangsaan Malaysia
43600 Selangor
Malaysia
E-mail: kina@ukm.edu.my
Khaidzir Ismail
Pusat Citra Universiti
Universiti Kebangsaan Malaysia
43600 Selangor
Malaysia
E-mail: izay@ukm.edu.my

Received: 22 March 2016

Accepted: 2 December 2016