

# Willingness to Pay for Cancer Genetic Testing in a Tertiary Healthcare Centre

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## ABSTRACT

**INTRODUCTION:** Increasing use of predictive genetic testing to address hereditary cancer risk has been commonly assessed by cost sharing practices. Little is known about how demographics, knowledge, attitude and practices may influence these individuals' willingness to pay for cancer genetic testing. The objective of this research was to determine factors associated with willingness to pay for cancer genetic testing.

**MATERIALS AND METHODS:** A self-administered questionnaire was distributed to 175 respondents in the oncology and day care unit in one of tertiary healthcare centre. The respondents comprised cancer patients, their family members and the community.

**RESULTS:** A total of 117 (66.9%) participants were willing to pay for cancer genetic testing. Ninety three (79.5%) of respondents were willing to pay from their own pocket with a mean of MYR1201.77 (SD976.72) and 95 (54.3%) respondents were willing to pay, shared with insurance. There were significant associations between willingness to pay with status of respondent as patients or family members or community, gender, race, educational level, income, knowledge and attitude. **CONCLUSION:** This is the first study to evaluate factors associated with willingness to pay not only among cancer patients but also their family members and the community. These findings reveal that majority of respondents believe there is valuable personal benefit based on genetic risk information and they are willing to pay for it.

### Keywords

Willingness to pay, Genetic testing, Cancer, Genetic

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## INTRODUCTION

Genetic test could reveal specific inherited changes, alterations or mutations in an individual's deoxyribonucleic acid (DNA), chromosomes or genes that may be harmful. A damage or mutation in the DNA could increase the chance or risk of developing diseases such as cancer.<sup>1</sup> Genetic test could provide a better understanding on the risks of developing diseases, determine their health care and medical treatment plans as well as adjusting their lifestyles. The genetic testing specifically for cancer is mostly recommended for people with family history of inherited cancer risk conditions.<sup>2</sup> Cancer genetic testing involves a pretested consultation with a doctor, genetic counsellor or other health professionals. Genetic counselling is

recommended prior and after the test to help the person manage their emotions and plan further effective actions.<sup>3</sup>

Willingness to pay (WTP) is a measure used in economic research to determine the successful rate of a programme or service. It represents an individual's capability in expending the maximum amount of money to equalize a utility change.<sup>4</sup> The drawn WTP construct has been used as a method of assessing individuals view on health care interventions. However, there is a scarcity in research study that address an individual's WTP for genetic test for cancer predisposition and its associated factors.

According to the International Agency for Research on Cancer, 43, 837 individuals out of 32.0 million populations in Malaysia, were diagnosed with cancer in 2018.<sup>5</sup> Based on the database of National Cancer Society Malaysia, the most common types of cancers were breast, colorectal, lung, cervical and nasopharyngeal cancers.<sup>6</sup> Despite the increasing number of cases in the country, cancer and genetic testing are not familiar among Malaysians, except for those in the medical profession. Yip et al. has reported that Malaysian women suffering from breast cancer have poor survival rate whereas an early diagnosis could have prevented half of the cancer-related mortality.<sup>7</sup> Breast cancer awareness is poor amongst Malaysian women and very few women were likely to attend regular mammography screening.<sup>7</sup> Besides, some of them also believe in cancer fatalism and alternative medicine and many have lack of autonomy in the decision making. This has also led to delay in seeking proper treatment and evidence-based medicine. Genetic testing for cancers shows that 15% of breast cancer patients were reported to have a family history of breast and ovarian cancers.<sup>8</sup> A cross-sectional study involving 131 high-risk women with a family history of breast cancer showed that 71% women had poor knowledge regarding the risk factor of breast cancer.<sup>9</sup> According to Yip et al., genetic counselling and genetic testing were accepted by 82% of women with high risk for hereditary breast and ovarian cancer syndromes.<sup>7</sup> However, only 78% of the carriers had inform their status to their respective families and merely 11% of the relatives had come forward to take the predictive testing although the genetic counselling and testing were free of charge.<sup>7</sup> Previously, the genetic testing and risk management clinic at University Malaya Medical Centre (UMMC) had offered genetic screening for their high-risk breast and ovarian cancer families. Their record showed that only 63.5% of eligible women chose to attend this clinic whereas 24% chose to have risk-reducing mastectomy and the rest had chosen breast surveillance. For ovarian cancer, only 63% of the target chose to have the risk-reducing salpingo-oophorectomy.<sup>7</sup>

Most of the individuals does not have any positive family history of the cancer nor do they have any real perception on the disease. In such scenario, unsurprisingly there will be an unwillingness to pay for the genetic testing for cancer risk. Amongst the

pertinent questions that may arise include: How much would people be willing to self-pay for the service? How would various demographic characteristics or knowledge, attitude and practice have impact on the individuals' WTP? Their responses would be essential to the public health practitioners in planning interventions to guide the public to be well-informed and to make balanced decisions regarding on undertaking the genetic testing for cancer risk.

The main objective of this study was to determine factors associated with WTP for cancer genetic testing.

## **MATERIALS AND METHODS**

This study was conducted at one of the tertiary health care centres from January until February, 2017. The target population comprised of all types of cancer patients and the immediate person who accompanied them to the oncology clinic and day-care unit. Universal sampling was used, and a total of 205 questionnaire was distributed. Those who did not provide consent and unfit to participate were excluded from the study.

The socio-demographic information included were gender, race, religion, marital status, number of children, educational status, monthly income and status of health insurance. Personal history of cancer was documented in addition to the record on family history of cancer amongst first-degree and the extended relatives. General knowledge on cancer was evaluated using eight items. The responses of 'Yes' and 'No' or 'Not-Sure' was scored as '1' or '0', respectively. The total score obtained was then classified into low (0-4), and high (5-8) level of knowledge. General knowledge of genetics and genetic testing was evaluated with ten items, respectively. It was scored 1 for 'Yes' and 0 for 'No' or 'Not Sure' response. The total score was classified into low (0-5), and high (6-10) level of knowledge. Attitude towards genetic testing was evaluated with thirteen items. It was scored on a 5-Likert Scale: Not Related (0), Strongly Disagree (1), Disagree (2), Neutral (3), Agree (4) and Strongly Agree (5). The total score was classified into negative (0-32), and positive (33-65) attitude. Genetic testing practices for cancer predisposition were assessed with thirteen items if the respondents have undergone genetic testing. Information collected included source of information on genetic testing, source of referral pre and post-test for

genetic counselling availability and the process of seeking informed consent. These were scored as '1' for Yes, '2' for No and '3' for Not Sure. Additionally, they were also asked for the location in which the genetic testing was undertaken. Besides, other questions were also included such as whether they shared their results with family members, do they cascade genetic testing amongst family members was performed, do they received emotional support from a genetic counsellor and family members, or whether they practiced healthy lifestyle. Generally, the WTP for cancer genetic testing was evaluated based on these seven items. Respondents were inquired on their WTP for cancer genetic testing and the amount of contribution if they were willing to do so. Data were analysed statistically using SPSS version 22 and p-value of <0.05 were considered as statistically significant.

## RESULTS

A total of 175 respondents completed the questionnaires, with the response rate being 87.5%. Almost half of the respondents were cancer patients (86, 49.1%). Eighty-five (48.6%) respondents were between the age of 40 and 60 years old with a mean age of 49.29 years old (SD 15.16). Majority of the respondents were female (135, 77.1%), Malay (125, 71.4%), Muslim (127, 72.6%) and married (133, 76.0%). Among the respondents, 87 (49.7%) of them were university graduates. The respondents' income ranged from MYR 2000 - MYR 30000 with the mean income of MYR 3756.00 (SD 3672.21). Additionally, 78 (44.6%) respondents earned less than MYR3000 and 63 (36.0%) respondents earned between MYR3001 - MYR5000. Moreover, only 59 (33.7%) respondents had private

**Table 1** Factors Associated with Willingness to Pay (WTP) in General (n=175)

	WTP n (%)	Not WTP n (%)	$\chi^2$	p-value
<b>Sociodemographic</b>				
Status of Respondent			5.801	0.055
Patient	50 (58.1)	36 (41.9)		
Family	43 (75.4)	14 (24.6)		
Community	24 (75.0)	8 (25.0)		
Age			7.708	<b>*0.021</b>
<40	35 (77.8)	10 (22.2)		
40-60	59 (69.4)	26 (30.6)		
>60	23 (51.1)	22 (48.9)		
Gender			1.552	0.213
Male	30 (75.0)	10 (25.0)		
Female	87 (64.4)	48 (35.6)		
Marital Status			2.064	0.151
Unmarried	22 (78.6)	6 (21.4)		
Married	95 (64.6)	52 (35.4)		
Number of Children			0.181	0.671
< 3	79 (65.8)	41 (34.2)		
≥ 3	38 (69.1)	17 (30.9)		
Education Level			9.977	<b>*0.002</b>
Low	49 (55.7)	39 (44.3)		
High	68 (78.2)	19 (21.8)		
Income			6.770	<b>*0.009</b>
<5000	82 (61.7)	51 (38.3)		
≥5000	35 (83.3)	7 (16.7)		
Health Insurance			1.458	0.227
Yes	43 (72.9)	16 (27.1)		
No	74 (63.8)	42 (36.2)		
Family History of Cancer			4.821	<b>*0.028</b>
Yes	48 (58.5)	34 (41.5)		
No	69 (74.2)	24 (25.8)		
<b>Knowledge on Cancer</b>				
Low Knowledge	11 (42.3)	15 (57.7)		
High Knowledge	106 (71.1)	43 (28.9)		
<b>Genetic</b>			8.150	<b>*0.004</b>
Low Knowledge	42 (55.3)	34 (44.7)		
High Knowledge	75 (75.8)	24 (24.2)		
<b>Genetic Testing</b>			5.919	<b>*0.015</b>
Low Knowledge	58 (59.2)	40 (40.8)		
High Knowledge	59 (76.6)	18 (23.4)		
<b>Attitude</b>			4.812	<b>*0.028</b>
Negative Attitude	3 (33.3)	6 (66.7)		
Positive Attitude	114 (68.7)	52 (31.3)		
<b>Practice</b>			1.612	0.204
Yes	7 (87.5)	1 (12.5)		
No	110 (65.9)	57 (34.1)		

health insurance while ninety-three (53.1%) respondents had family history of cancer. Potential demographic and psychosocial predictors of WTP for cancer genetic testing were as shown in Table 1.

In general, 117 respondents (66.9%) reported that they were WTP for cancer genetic testing (Table 1). Among these, 93 respondents (79.5%) were willing to self-pay with a mean of MYR1201.77 (SD 976.72) and 95 respondents (54.3%) were WTP if the total cost was shared with the insurance provider. One hundred and thirty-eight respondents (78.9%) were WTP for cancer genetic testing if they were given full coverage from the insurance and 146 respondents (83.4%) were WTP if it was fully covered by the government.

The results showed that there were 85.1% respondents with high knowledge on cancer with a mean score of 5.29 (SD 1.51) and cancer patients (69) being the majority of the respondents. Furthermore, 41 (41.4%) patients had high knowledge on genetics followed by 39 (39.4%) family members, and 19 (19.2%) community members. Only 77 (44.0%) respondents had high knowledge on genetic testing with a mean score of 4.73 (SD 2.95 with patients being the highest in the list (50.6%) followed by family members (33.8%), and community members (15.6%). One hundred and sixty-six (94.9%) respondents showed positive attitude towards cancer genetic testing in which majority of the respondents were patients (48.2%), followed by family members (33.1%), and community members (18.7%). Nonetheless, only 8 respondents (4.6%) underwent cancer genetic testing in which 3 of them were patients and another five were family members.

Overall, there was significant association between WTP and age ( $p=0.021$ ), educational level ( $p=0.002$ ), income ( $p=0.009$ ) and family history of cancer ( $p=0.028$ ). The WTP was higher among respondents aged less than 40 years old, highly educated, with monthly income of less than MYR5000 and without family history of cancer (Table 1). Furthermore, the present study showed that there were significant associations between WTP and knowledge on cancer ( $p=0.004$ ), genetics ( $p=0.004$ ), as well as genetic testing ( $p=0.015$ ). The percentage of respondents who were WTP was higher among respondents with high knowledge compared to the respondents who had lower knowledge. There were a

significant association between the WTP and attitude ( $p=0.028$ ) in which the percentage of individual's WTP was higher among individuals with positive attitude. Notably, the percentage of individual's WTP was higher among those who practiced genetic testing, but the association was not significant ( $p=0.204$ ).

In specifically among patients, the WTP were also assessed based on the same factors. Table 2 shows significant association between WTP and income ( $p=0.024$ ). Cancer patients with income more than MYR5000 shows a higher percentage of WTP compared to patients with income less than MYR5000. Furthermore, there were also significant associations between WTP and knowledge on cancer ( $p=0.007$ ), on genetics ( $p=0.007$ ) and on genetic testing ( $p=0.019$ ). The percentage of WTP was higher among patients with high knowledge compared to the patients with lower knowledge. There was also significant association between WTP and attitude ( $p=0.033$ ), in which the percentage of WTP was higher among patients with positive attitude. However, there was no significant association between WTP and practice of cancer genetic testing.

From the total number of respondents, 57 of them were family members and 32 of the respondents were from the community. None of the socio-demographic, knowledge, attitude or practice factors were found to have significant association with the WTP for cancer genetic testing among family members and community members.

Based on the results obtained from the bivariate analysis above, all factors with  $p<0.25$  were selected and further proceed with the multivariate analysis in general, among patients, family members and community as stated by Bursac et al.<sup>10</sup> Table 3 shows the determinant factors influencing the WTP for cancer genetic testing based on the Multiple logistic regression analysis. The analysis shows that only knowledge for genetic testing was found to be significant for WTP for cancer genetic testing in general ( $p=0.004$ ) and among patients ( $p=0.013$ ). However, knowledge for genetic testing was found not to be significant with WTP for cancer genetic testing among family members and community. The Nagelkerke's  $R^2$  calculated was 0.255 and 0.293 respectively. The remaining 74.5% and 70.7% may be

**Table 2** Factors Associated with Willingness to Pay (WTP) among Patient (n=86)

	WTP n (%)	Not WTP n (%)	$\chi^2$	<i>p</i> -value
<b>Sociodemographic</b>				
<b>Age</b>			4.255	0.119
<40	3(50)	3(50)		
40-60	32(68.1)	15(31.9)		
>60	15(45.5)	18(54.5)		
<b>Gender</b>			1.042	0.394#
Male	4 (80.0)	1(20.0)		
Female	46 (56.8)	43 (43.2)		
<b>Marital Status</b>			0.786	0.569#
Unmarried	1 (33.3)	2 (66.7)		
Married	49 (59.0)	34 (41.0)		
<b>Number of Children</b>			3.013	0.083
< 3	30 (51.7)	28 (48.3)		
≥ 3	20 (71.4)	8 (28.6)		
<b>Education Level</b>			3.278	0.070
Low	28 (50.9)	27 (49.1)		
High	22 (71.0)	9 (29.0)		
<b>Income</b>			5.117	<b>*0.024</b>
<5000	34 (51.5)	32 (48.5)		
≥5000	16 (80.0)	4 (20.0)		
<b>Health Insurance</b>			0.011	0.915
Yes	12 (57.1)	9 (42.9)		
No	38 (58.5)	27 (41.5)		
<b>Family History of Cancer</b>			1.376	0.241
Yes	20 (66.7)	10 (33.3)		
No	30 (53.6)	26 (46.4)		
<b>Knowledge on Cancer</b>			7.185	<b>*0.007</b>
Low Knowledge	5 (29.4)	12 (70.6)		
High Knowledge	45 (65.2)	24 (34.8)		
<b>Genetic</b>			7.274	<b>*0.007</b>
Low Knowledge	20 (44.4)	25 (55.6)		
High Knowledge	30 (73.2)	11 (26.8)		
<b>Genetic Testing</b>			5.468	<b>*0.019</b>
Low Knowledge	22 (46.8)	25 (53.2)		
High Knowledge	28 (71.8)	11 (28.2)		
<b>Attitude</b>			4.558	<b>*0.033</b>
Negative Attitude	1 (16.7)	5 (83.3)		
Positive Attitude	49 (61.2)	31 (38.8)		
<b>Practice</b>			0.093	1.000#
Yes	2 (66.7)	1 (33.3)		
No	48 (57.8)	35 (42.2)		

\*significant level at  $p < 0.05$

#Fisher's Exact Test

contributed by other factors not included in the current study. Assumptions were also checked by assessing the goodness of fit of the model using the Hosmer-Lemeshow test with  $p=0.610$  and  $p=0.385$ , and a classification table reporting the overall percentages of correctly classified were at 66.1% and 72.1% respectively.

From the total number of respondents, 57 of them were family members and 32 of the respondents were from the community. None of the socio-demographic, knowledge, attitude or practice factors were found to have significant association with the WTP for cancer

genetic testing among family members and community members.

Based on the results obtained from the bivariate analysis above, all factors with  $p < 0.25$  were selected and further proceed with the multivariate analysis in general, among patients, family members and community as stated by Bursac et al. <sup>10</sup> Table 3 shows the determinant factors influencing the WTP for cancer genetic testing based on the Multiple logistic regression analysis. The analysis shows that only knowledge for genetic testing was found to be significant for WTP for cancer genetic testing in general ( $p=0.004$ ) and among patients ( $p=0.013$ ). However, knowledge for genetic testing was found not to be significant with WTP for cancer genetic testing among family members and community. The Nagelkerke's  $R^2$  calculated was 0.255 and 0.293

**Table 3** Factors Associated with WTP in General, among Patients, Family Members and Community using Multivariate Logistic Regression Analysis

Variable	Regression coefficient (b)	Std error	Wald (z)	Adjusted odds ratio (95% CI)	<i>p</i> -value
<b>General</b>					
Knowledge on Genetic Testing	1.072	0.372	8.313	1.409 - 6.052	<b>0.004</b>
Constant	-3.461	2.982	1.348		0.246
<b>Patients</b>					
Knowledge on Genetic Testing	-1.255	0.507	6.129	0.106- 0.770	<b>0.013</b>
Constant	-10.317	3.713	7.719		0.005

respectively. The remaining 74.5% and 70.7% may be contributed by other factors not included in the current study. Assumptions were also checked by assessing the goodness of fit of the model using the Hosmer-Lemeshow test with  $p = 0.610$  and  $p = 0.385$ , and a classification table reporting the overall percentages of correctly classified were at 66.1% and 72.1% respectively.

## DISCUSSION

The increasing availability of cancer genetic testing suggests that genetics development will slowly permeate into clinical practices beyond providing the traditional genetic services.<sup>11</sup> An increasing number of people using genetic services may be associated with their exposure to the current advancement in cancer genetics which impacts various decision-making

processes. The efficiency in utilising this advancement and making decision regarding the genetic risks will be depending on the individual's knowledge and attitude towards human genetics and its development.<sup>11</sup>

Majority of the respondents in this study were WTP for cancer genetic testing. This attitude was similar to the previous study on WTP but for inherited retinal disease in which majority of the participants were willing to undertake the genetic testing.<sup>12</sup> Our study population was largely composed of middle-aged group in which majority of them were unemployed, had no source of income or was not aware of the cost of cancer genetic testing. Interestingly, more than half of the respondents were WTP for the test due to their heightened awareness that managing cancer is physically, mentally and financially challenging. Thus, more respondents were WTP for cancer genetic testing to know their risk level of having cancer.

Previous study by Henneman et al. has reported that knowledge on cancer genetics and genetic testing as well as their attitude towards these were high among the study's respondents.<sup>13</sup> This supports our current finding showing more respondents were knowledgeable regarding this and has positive attitude towards the use of genetic test.<sup>13</sup> However, the practice of genetic testing is scarce especially in Malaysia due to little exposure and awareness towards such test compared to other developed countries.<sup>14</sup>

In general, family members should have higher WTP for genetic testing among the three categories of respondents. There were mixed findings from other studies regarding this. A review on the role of cancer worry in cancer screening behaviours found that majority of the people ranging from the high-risk to general population samples were not concerned about cancer.<sup>15</sup> A negative relationship between cancer worry and screening was also observed as cancer worry was generally defined as fear about positive test result rather than worrying about the chances of developing cancer. Their worry also include carrying a retrospective attitude rather than being optimistic about the outcome. Nevertheless, when cancer worry is defined and measured as general worries about cancer, it is commonly related to the increased utilization of genetic

screening tests.<sup>15</sup> A study on the factors influencing an individual's WTP for BRCA1/2 genetic testing found that the subjects WTP was positively correlated with their numeracy and perceived risk.<sup>16</sup>

Current findings on the significant positive association between WTP and factors on knowledge was further supported by a previous study showing significant association between higher education levels with higher WTP.<sup>17</sup> This could be due to individuals with higher education who were more keen to inquire about the genetic testing thus gaining better knowledge on the genetic testing. There was also an association between the respondents' income with WTP for cancer genetic testing. Our results on association between the WTP and respondents' income were similar to Tubeuf et al., who did a study on WTP for inherited retinal disease genetic testing.<sup>18</sup> Besides, other studies have also reported a positive association between income and WTP for varied types of genetic testing.<sup>19,20,21,22</sup>

The significant association between WTP and knowledge on cancer, genetics and genetic testing among cancer patients is not surprising. They were more prepared to receive more information regarding the cancer as well as about both the cancer genetics and genetic testing. This is similar to the finding reported by Sinead et al. on WTP for pharmacogenomics testing, in which the WTP was higher among patients who had better understanding on genetic testing.<sup>23</sup> Interestingly, attitude was significantly associated with WTP in current study. Jennifer et al. found that individuals with more positive attitudes towards genetic testing and cancer screening were more WTP for these services.<sup>24</sup>

This study was a pilot study which involved a small sample size that were recruited from a single institution. Future study involving larger sample size and recruitments from a multi-centric setting could provide more robust findings and supports current findings.

## CONCLUSION

This pioneering study in Malaysia had addressed the WTP for cancer genetic testing based on the knowledge, attitude, and practice amongst not only cancer patients, but also among family members of cancer patients and

the overall community. Current findings could provide overview on new perspectives and expectations from individuals other than the cancer patients on WTP.

## CONFLICT OF INTEREST

None of the authors have any conflicts of interest to declare.

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