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Attitude and awareness of public towards genetic testing in Riyadh, Saudi Arabia

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ABSTRACT

The current study was designed to evaluate the attitude of the Saudi general population towards knowledge, perception and awareness about genetic testing. Using a convenience sampling technique, an online survey was used to collect the data. The survey consisted of 16 questions that covered basic demographics and several scenarios that assess subjects' perceptions regarding genetic testing. Answering all questions was required for completing the survey. Among 333 subjects, 53.5% were male, 18.9% were married, and 99.4% were muslims. Around 75% has/will have a bachelor degree. About 59% were students. About 87% would consider genetic testing before marriage and similar percentage would not consider conceiving a child if the genetic screening indicated that there is 100% chance the child will be born with genetic disorder. Neither marital status (Single = 87.04%, married = 87.30% ($P = 0.955$)) nor gender (male = 85.96, female = 88.39 ($P = 0.509$)) affected the aforementioned decision. When subjects were asked if they would choose abortion knowing that the embryo has a severe genetic disorder, 62.7% answered yes. In general, 80.4% were willing to be recruited into a genetics study, married subjects were more reluctant to be recruited compared to singles (30% and 17% ($P = 0.018$) respectively). There was no difference between males and females in the decision of joining a genetic study. Also 78.4% supported creation of genetic disease database and family maps. 69.7% of the participants supported government enforcement of the genetic testing, 56.2% supported government-run facilities for Saudi citizens to have genetic tests. We conclude that married people were in favor of genetic testing than the single counterparts, secondly, single status people supported the idea of having genetic tests before their marriage they were supportive of the idea of the government taking a leading role in enforcing the genetic testing and creation of the genetic banks.

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1. Introduction

Genetic testing is an important medical diagnostic technique that detects heritable changes or variations in gene sequences or chromosome structures, which is reflected in the altered expression of proteins thereof. The outcome from such test can identify the altered gene or chromosome and hence can help to determine an individual's chances of developing genetic disorders (Katsanis

and Katsanis, 2014). These days, several methods are employed for genetic testing: First, molecular genetic tests which usually study single genes or short lengths of DNA to identify mutations or genetic variations which result in genetic disorders (Deng et al., 2014). Second, Chromosomal genetic tests which analyze long lengths of DNA or whole chromosomes to see if there are huge genetic variations, e.g., an extra copy of a chromosome, that can cause an abnormal genetic condition (Xie et al., 2018). Third, genetic tests based on biochemical methods which check the expression of the affected genes at the level of proteins. Unusual results in any of the above three can indicate heritable changes in the DNA that primarily manifests in genetic disorder (Zimmern and Kroese, 2007).

Recent past has witnessed a tremendous boom in the knowledge about health, diseases and the information about genomic data also has increased substantially, with the advent of technology and online databases. This has led to a huge increase in the

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knowledge and awareness of the general population about various aspects of genetic testing (Zhao and Grant, 2011). Globally each and every community has its own set of beliefs, values, customs, and interests and the Saudi society is no exception to this. With every new “idea” the community, depending upon its set of nuances, either embraces or rejects the alien ideas. Driven by traditional beliefs some new ideas are sometimes rejected by a community even if it is beneficial for the larger good of the community. Many factors affect the decision of the traditional communities like the idea being way ahead of its time, the idea not being introduced properly, bad past experiences with similar ideas, or the normal fear of everything that is new and the tendency to resist change.

Current developmental trends in genomics have continuously lead to the enhancement of the quality of life for a number of disorders by enabling the availability of cheap, easy and fast genetic testing either through the primary health care system or as newborn screening panels or via direct-to-consumer (DTC) testing on the internet (Borry et al., 2010; Calsbeek et al., 2007). There is a list of tests undertaken for proper detection of genetic diseases at different phases of human life e.g. detection of congenital malformations and chromosomal abnormalities at prenatal level, screening of newborn babies for metabolic, endocrine and hematological disorders, screening for carriers of inherited disorders and screening of individuals with a familial history of different type of cancers (WHO, 1999; Catz et al., 2005; Michie et al., 2004). With new advances in genetic testing a differential decision for the predisposition to diseases are becoming applicable for numerous diseases, e.g., dementia, diabetes and cancer etc. (Eum et al., 2018; Henneman et al., 2004; Henneman et al., 2013; Vermeulen et al., 2014). There is a surge of interest among health care policy makers and researchers in analyzing the public attitude towards continuous advancement in the development of genetic testing.

The attitude of public towards genetic testing for assessing the risk of diseases is generally encouraging and positive (Oliveri et al., 2016; Hann et al., 2017; Etchegary, 2014). However, as already mentioned in the Saudi community because of many taboos and traditional beliefs we need to understand the status in the Saudi community regarding genetic screening. The Saudi community might be interested in genetic testing and screening, because it might affect many of the Saudi community norms, like marriage decisions, abortion, divorce, and decision to have more kids or even to have kids at all. Once we understand the status, we can design educational programs to motivate the Saudi community about the benefits and the importance of genetic screening, how to overcome the fears that can improve the cooperation of Saudi citizen with future governmental regulations about genetic screening. As reported, in one of the studies conducted in US, Haga et al., (2013) reported that 97% of total participants showed interest in the area of genetic testing and most of the participants showed a positive attitude towards the use of genetic testing as a toll for detection of diseases. A Dutch survey conducted by also reported a positive attitude of the population towards genetic testing, as per their study 64% of participants agreed that genetic testing can help live longer. Another study conducted in African-Americans (Laskey et al., 2003) revealed a positive view about genetic testing for preventive care and presymptomatic detection with some concerns with respect to privacy.

The present investigation aimed to answer/know the following questions:

1. What is the level of Knowledge, Perception and Awareness of Saudi General population about Genetic testing?
2. What is the attitude of Saudi's about the screening pre and post birth?
3. What is the level of awareness about the Government offered genetic services in Saudi Arabia?

2. Material methods

2.1. Study population

This is a descriptive study, in which we used a non-probability convenience sampling technique. The study was conducted at King Saud University (KSU), Riyadh, Saudi Arabia between August–October 2014.

2.2. Study questionnaire

The study was conducted using a self-administered, pre-designed and validated electronic questionnaire. The survey questionnaire dispensed to collect the data consisted of 3 sections: 1) a brief idea on the study and general instructions on how to fill the survey, 2) demographic information (age, gender, marital status, monthly income, level of education), and 3) 16 questions to identify the participants knowledge, attitudes, and concerns about the genetic testing. Basic Information section contained individual's socio-demographic characteristics such as age, gender, marital status, education level etc [Table 1]. The electronic survey was programmed not to move to the next question without selecting an answer and cannot go back to the previously answered question.

2.3. Sample size

The required sample size was calculated at the 95% confidence level with an estimated 40.0% prevalence of awareness regarding genetic testing and a margin of error $\pm 5\%$. The necessary determined sample size has to be 280. However, the final sample size of 330 was taken into account for a 10% non-response rate.

2.4. Ethical approval

The study was approved by “Institutional Research Board”, King Saud University, Riyadh, Saudi Arabia.

2.5. Analysis of data

The responses to the questionnaires were saved on PIs PC at KSU campus. The data was entered in MS Excel and before the analysis; the dataset was prepared and checked for missing data. SPSS software was used for the analysis. Chi-square test was used for the analysis of data. Descriptive statistics (e.g. mean and standard deviation) were used to describe continuous variables while categorical variables were presented in frequencies and percentages. Independent sample *t*-test was used to determine the mean score differences of the awareness, knowledge sections between genders and medical and non-medical faculties. The confidence was set at 95%, Statistical significance was determined at $p < 0.05$ and entered into the Statistical Package for the Social Sciences (SPSS) program. All data were analyzed and summarized in the form of frequencies and percentages.

3. Result

3.1. The study population

The study was carried out on students of Medicine attending Basic Medical Science Department at King Saud University (KSU). A total of 333 responses were received in response to the online cross-sectional survey from various sections of the society in Riyadh, Saudi Arabia.

Table 1
Univariable and Bivariable Analyses of basic characteristics and differences regarding genetics-related questions between males and females (N = 333).

Characteristics	Male n = 178 n (%)	Female n = 155 n (%)	Total N = 333 N (%)	P-Value
Education				
Post-Graduate	6 (3.4)	8 (5.2)	14 (4.2)	0.505
University	138 (77.5)	111 (71.6)	249 (74.8)	
High school	31 (17.4)	32 (20.6)	63 (18.9)	
Intermediate school	2 (1.1)	4 (2.6)	6 (1.8)	
Read and write only	1 (0.6)	0 (0)	1 (0.3)	
Marital status				
Single	138 (77.5)	132 (85.2)	270 (81.1)	0.076
Married	40 (22.5)	23 (14.8)	63 (18.9)	
Occupation				
Student	96 (53.9)	100 (64.5)	196 (58.9)	0.001
Employee	63 (35.4)	28 (18.1)	91 (27.3)	
I do not work	17 (9.6)	27 (17.4)	44 (13.2)	
Retired	2 (1.1)	0 (0)	2 (0.6)	
Religion				
Muslim	177 (99.4)	154 (99.4)	331 (99.4)	0.922
Non-Muslim	1 (0.6)	1 (0.6)	2 (0.6)	
Questions related to genetics				
Q1: Decision to have another child knowing that he has a genetic disease 100% (yes)	25 (14)	18 (11.6)	43 (12.9)	0.509
Q2: Divorce decision due to child stricken (yes)	31 (17.4)	34 (21.9)	65 (19.5)	0.299
Q3: Abortion decision (yes)	109 (61.2)	100 (64.5)	209 (62.8)	0.537
Q4: Decision to do genetic testing before marriage (yes)	157 (88.2)	128 (82.6)	285 (85.6)	0.145
Q5: Decision to have another child knowing that he has a genetic disease 100% (yes)	25 (14)	18 (11.6)	43 (12.9)	0.509
Q6: Divorce decision due to child stricken (yes)	31 (17.4)	34 (21.9)	65 (19.5)	0.299
Q7: Decision to abort a child (yes)	109 (61.2)	100 (64.5)	209 (62.8)	0.537
Q8: Decision to do genetic testing before marriage (yes)	157 (88.2)	128 (82.6)	285 (85.6)	0.145
Q9: Participated in genetic study (yes)	5 (2.8)	5 (3.2)	10 (3)	0.824
Q10: Willingness to participate in genetic testing study (yes)	140 (78.7)	128 (82.6)	268 (80.5)	0.367
Q11: Genetic bank lead to race superiority (yes)	56 (31.5)	54 (34.8)	110 (33)	0.513
Q12: Genetic bank lead to cure for rich only (yes)	63 (35.4)	55 (35.5)	118 (35.4)	0.986

3.2. Demographics

Of the 333 participants, 178 were males and 155 were females. Additionally, 249 of the participants (74.8%) were of University educated level while 63 (18.9%) were of high school level. Also, 91 (27.3%) were employed in some jobs while 196 (58.9%) were still, students. Most of the participants in this study were practicing Muslims (331, 99.4%). The various demographic details of the participants are tabulated in [Table 1](#).

3.3. Marital status

Of the total 333 participants, 270 (81.1%) were single and only 63 (18.9%) were married at the time of the study. Furthermore, among single status participants 138 (51.1%) were males and 132 (48.9%) were females; and among married participants 40 (63.5%) were males and 23 (36.5%) were females.

3.4. Decision to have another child knowing that he has a genetic disease?

On a very affirmative level of awareness, 290 (87.1%) of the participants responded that they would not have another child if they know of it having a genetic disease [[Table 2](#)]. The responses by both males and females were comparable in the decision. Also, married people were of similar opinion with 55 (87.3%) responding with No as answer [[Table 3](#)].

3.5. Decision to divorce knowing the child is stricken with a genetic disease?

Majority of the participants 268 (80.5%) were of the opinion that divorce was not an option if they knew that their child was having any form of genetic diseases [[Table 2](#)]. However, married

people were more of altruistic behavior with only 8 (12.7%) of them choosing divorce as an option whereas 57 (21.1%) of single status respondents opted for divorce as answer [[Table 3](#)].

3.6. Decision to have abortion knowing the child is stricken with a genetic disease?

Majority of the participants 209 (62.8%) opted for the abortion as the choice, in case they knew that their child is going to be born with genetic defect [[Table 2](#)]. Single participants 176 (65.2%) were of more strong opinion about choosing abortion as an answer in comparison to married ones (52.4%). A total of 118 (35.4%) of the participants strongly agreed with the decision with the option of abortion for this query [[Table 3 and 4](#)].

3.7. Decision to undergo genetic testing before marriage?

Majority of the participants (285, 85.6%) responded with positive agreement to have genetic testing before marriage [[Tables 2 and 3](#)]. Furthermore, 261 (78.4%) of the participants were of the opinion that government should create a database of genetic diseases and map families accordingly, however a minority 42 (12.6) of the respondents feared that the information contained in the genetic banks will be prone to leakage and lead to unethical consequences [[Fig. 1](#)].

3.8. Need for government enforcing of the genetic testing studies.

Majority of the participants (232, 69.7%) strongly agreed with the option of government enforcement of the genetic testing. Among them 187 (69.3%) were of single status while 45 (71.4%) were married [[Tables 2 and 5–6](#)]. Furthermore, 187 (56.2%) of the participants responded with affirmation that there should be government-run facilities for Saudi citizens to have genetic tests,

Table 2
Question wise distribution of the participant's frequency as per marriage.

	Single No. (%)	Married No. (%)	Total No. (%)	P-Value
Questions related to genetics				
Q1: Decision to have another child knowing that he has a genetic disease 100% (yes)	35 (13)	8 (12.7)	43 (12.9)	0.955
Q2: Divorce decision due to child stricken (yes)	57 (21.1)	8 (12.7)	65 (19.5)	0.129
Q3: Abortion decision (yes)	176 (65.2)	33 (52.4)	209 (62.8)	0.058
Q4: Decision to do genetic testing before marriage (yes)	234 (86.7)	51 (81)	285 (85.6)	0.245

Table 3
Participants decision on abortion.

	Male n (%)	Female n (%)	Total N (%)	P-Value
Strongly Agree	63 (35.4)	55 (35.5)	118 (35.4)	0.795
Agree	42 (23.6)	29 (18.7)	71 (21.3)	
Disagree	14 (7.9)	13 (8.4)	27 (8.1)	
Strongly disagree	8 (4.5)	6 (3.9)	14 (4.2)	
I do not know	51 (28.7)	52 (33.5)	103 (30.9)	
Total	178 (100)	155 (100)	333 (100)	

Table 4
Participants decision on Govt. enforcement of genetic testing.

	Male n (%)	Female n (%)	Total N (%)	P-Value
Strongly Agree	128 (71.9)	104 (67.1)	232 (69.7)	0.696
Agree	28 (15.7)	32 (20.6)	60 (18)	
Disagree	8 (4.5)	8 (5.2)	16 (4.8)	
Strongly disagree	3 (1.7)	1 (0.6)	4 (1.2)	
I do not know	11 (6.2)	10 (6.5)	21 (6.3)	
Total	178 (100)	155 (100)	333 (100)	

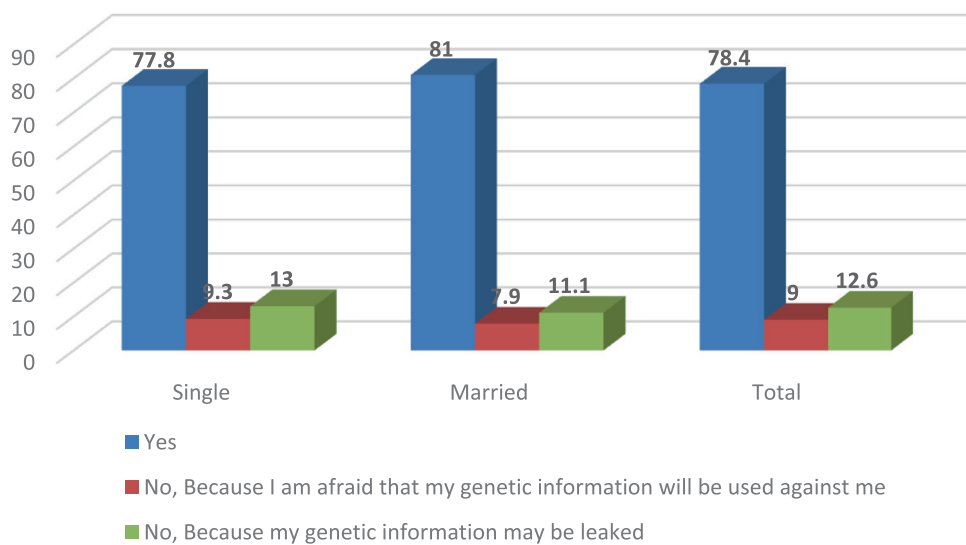


Fig. 1. Responses to the question for creating genetic database under government. Responses are in percentages.

Table 5
Participants perception of the genetic map for family.

	Male n (%)	Female n (%)	Total N (%)	P-Value
Strongly Agree	87 (48.9)	92 (59.4)	179 (53.8)	0.005
Agree	60 (33.7)	42 (27.1)	102 (30.6)	
Disagree	5 (2.8)	11 (7.1)	16 (4.8)	
Strongly disagree	9 (5.1)	0 (0)	9 (2.7)	
I do not know	17 (9.6)	10 (6.5)	27 (8.1)	
Total	178 (100)	155 (100)	333 (100)	

Table 6
Participants perception for genetic map for newborns.

	Male n (%)	Female n (%)	Total N (%)	P-Value
Strongly Agree	81 (45.5)	64 (41.3)	145 (53.8)	0.931
Agree	56 (31.5)	55 (35.5)	111 (42)	
Disagree	8 (4.5)	6 (3.9)	14 (4.2)	
Strongly disagree	2 (1.1)	2 (1.3)	4 (1.2)	
I do not know	31 (17.4)	28 (18.1)	59 (17.7)	
Total	178 (100)	155 (100)	333 (100)	

but 53 (15.9%) of them feared that the information might be accessible to insurance companies which may affect citizens negatively [Fig. 2].

4. Discussion

This study compares public attitudes and awareness towards genetic testing in 2010, in Riyadh Saudi Arabia. The study further analyzed, that if the respondents valued the role of genetic testing in their decision making in many aspects of life e.g., having more children, divorce, abortion and finally if they believed that the government should establish the Genetic Testing Centers for mandatory testing and creation of databanks in Saudi Arabia.

The Kingdom of Saudi Arabia (KSA) is one of the major collaborators of the Gulf Cooperation council in the Arab Middle East and lies at the furthest part of southwestern Asia constituting four/fifths of the Arabian Peninsula (Qari et al., 2013). With a population of approximately 33 million by the end of 2018, which makes up about 0.44% of the world population it ranks 41st country in the world (Health statistic book, Saudi Arabia, 2018; World o Meter, 2019). Saudi Arabia is officially an Islamic country with 100% Muslim citizens. The legal and governmental system is based on traditional Islamic jurisprudence. Since Saudi culture and traditions are derived mainly from Islamic laws and influenced by tribal code of conduct, societal values are much inclined towards conservation (Qari et al., 2013).

Like many other Muslim majority states in the Middle East, the Saudi population has a high frequency of consanguineous marriages which has been assumed to be the single most important

factor leading to an increased frequency in homozygosity and genetic disorders due to the founder effect (Qari et al., 2013; Al-Owain et al., 2012; Alkuraya FS, 2014). The high incidence of various genetic diseases in Saudi population has created an increased demand for the compulsory premarital testing for genetic diseases, and newborn screening program in the Kingdom of Saudi Arabia (Altaany et al., 2019; Al-Owain et al., 2012; Habib et al., 2015).

Because of the conservative nature of the society, the newborn screening program was accepted however, the premarital screening program was a bit controversial and couples (90%) still decided to marry even after they received incompatible report after genetic testing (Habib et al., 2015). After considerable deliberation government passed a law in 2002 that mandates every citizen to undergo screening for hemoglobinopathies, thalassemias, and G6PDH deficiency prior to issuing a marriage contract (Alhamdan et al., 2007; Memish et al., 2011). Furthermore, the choice of genetic testing and the implications thereof become more contentious for those parents who have one or more children with a known diagnosed disease. For couples with such mind set, prenatal genetic testing becomes the only choice to solve the dilemma of having more children (Alkuraya and Kilani et al., 2001). Alkuraya et al., reported that nearly 45% of such couples opt for early prenatal diagnosis in comparison to 35% who choose pre-implantation genetic diagnosis (PGD) (Habib et al., 2015; Alkuraya FS, 2013).

Also, consanguinity can render itself evident and expressive as homozygous DNA variants especially for those mutations that arose as recently as two generations ago (first cousin marriage) because of which mutations get overrepresented and allelic heterogeneity is lost more aggressively (Alkuraya FS, 2013).

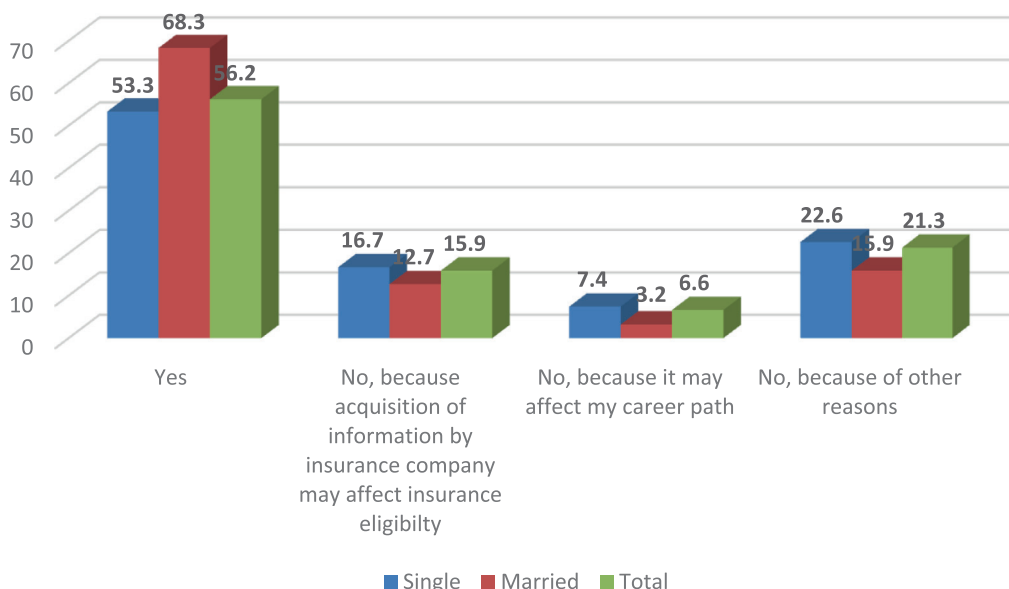


Fig. 2. Responses to the question for genetic database for Saudi citizens. Responses are in percentages.

In this study, 12.9% of the participants responded that they would still opt for another child even if he has confirmed genetic disease, and a majority of them (87.1%) disagreed. Also, majority of the participants 268 (80.5%) were of the opinion that divorce was not an option if they knew that their child was having any form of genetic disease, and majority of the participants 209 (62.8%) opted for the abortion as the choice, in case they knew that their child is going to be born with a genetic defect. These results show a positive attitude of the public towards their decision making after revelation by genetic testing and are in conformation with other studies (Alkuraya FS, 2014; Alkuraya and Kilani et al., 2001; Alkuraya, 2013; Aldahmesh et al., 2009; Alam, 2006; Hashemi-Soteh et al., 2019) but in contradiction with the study in Jordan (Abdo et al., 2018), but how much of this opinion gets reflected in practice is arguable. Furthermore, under current legislature in Saudi Arabia, therapeutic abortion is permitted provided it is performed within 120 days from the time of fertilization in order to comply with the Islamic view of the timing of ensoulment (Alkuraya, 2014; Khitam, 2013).

Also, 85.6% of the participants responded with a positive agreement to have genetic testing before marriage and 78.4% of the participants were of opinion that the government should create a database of genetic diseases and map families accordingly. Furthermore, 69.7% strongly agreed with the option of government enforcement of the genetic testing. Of them 187 (69.3%) were of single status while 45 (71.4%) were married. The results of this study showed that: firstly, married people were in favor of genetic testing than the single counterparts, secondly, single status people supported the idea of having genetic tests before their marriage to look for the compatibility and thirdly, they were supportive of the idea of the government taking a leading role in enforcing the genetic testing and creation of the genetic banks. These results are similar to already reported by other authors (Habib et al., 2015; Alhamdan et al., 2007; Memish et al., 2011).

This study provides insights regarding the attitude of the Saudi population towards genetic testing and how it affects their decision making in social and religious context. We found the overall attitude towards GT to be positive which is significant in affecting the wider concept of up taking personalized medicine. However, we carefully recommend more active efforts by the educated intellectual class, health care professions, care takers and teachers is needed to present the general public with all benefits, risks, as well as limitations of genetic testing; so as to ensure informed decision making. This becomes even important nowadays with the drastic advancement of the information technology and artificial intelligence. Furthermore, we also recommend that awareness programs on the value and specifics of personalized medicine need to be arranged by the government to overcome the knowledge gap among general public.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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