

*Original Research Article*

# Public attitudes and awareness towards Saudi Genome Program and Genetic Testing in Al Ahsa, Saudi Arabia

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## Abstract

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Saudi Arabia has a high prevalence of consanguineous marriage and genetic disorders. Saudi Human Genome Program is specifically mapping the genomes of Saudis to identify prominent genetic traits and characteristics of Saudi society. The success of the Saudi Genome Program is highly dependent on the Saudi population embracing the concept of participating in genetic testing. The study aimed to measure the knowledge of the Saudi population about the Saudi genome program and their attitude towards it. A descriptive cross-sectional study was conducted in Al Ahsa, Saudi Arabia, using a non-probability convenience sampling technique. Data was collected in November 2021. Participation is through an anonymous online survey. The questionnaire was created, validated, and produced electronically in Google Forms. A total of 316 participants completed the survey, representing 85.6%. More than half (56.3%) of the participants with high knowledge scores related to genetic testing and the Saudi genome project. (33.5%) of participants were aware of where genetic testing is performed. In terms of the future attitude toward genetic testing, (71.5%) expressed willingness to undergo genetic testing. The results of our study revealed that the majority of participants (82%) agreed that genetic counseling was important. The majority of participants (81.6%) had a positive outlook towards genetic testing and genome programs. In conclusion, this study delivers insight into the Saudi population's knowledge and attitudes regarding genetic testing and the Saudi Genome Program. Overall, the study found that attitudes towards genetic testing and the Saudi Genome Program were positive. Nevertheless, over half of the participants reported inadequate knowledge, which needs to be addressed in health education programs and media.

**Keywords:** Awareness, Attitude, Genetic testing, Saudi genome program, Saudi Population, Saudi vision 2030

## INTRODUCTION

Almost the entire Arabian Peninsula is covered by Saudi Arabia. In the region, most of the population is of Arab descent. Most of them are descendants of nomadic tribes that have traditionally inhabited the area. Saudi culture is fundamentally traditional and conservative (Cultural Atlas, 2021).

The current population of Saudi Arabia is near 35 million people (Worldometers, 2021). Until recently, Saudi Arabia has not been able to provide adequate data on the

health of its population and the quality of its healthcare. In 2010, Saudi Arabia began a major investment and transformation program in the healthcare sector (Tyrovolas et al., 2020).

Saudi Arabia is prone to a high incidence of autosomal recessive genetic disorders compared to other countries. Saudi Arabia has a high rate of consanguineous marriages and genetic disorders. There were records on the practices of Saudis toward prenatal diagnosis (PND)

(Al-Owain et al., 2012; AbdulAzeez et al., 2019).

Saudi Arabia's King Abdullah International Medical Research Center (KAIMRC) announced details about a first-of-its-kind project to map and categorize Saudi genomes to identify prominent genetic characteristics. As part of this project, they seek to establish standards for personalized medicine, which include categorizing patients according to their genetic disposition so that they can receive a more efficient and accurate treatment (Ministry of National Guard Health Affairs, 2020). As a result of the massive data rewards from the project, genetics and personalized medicine have advanced significantly during the 21st century (Raney et al., 2011).

The success of the Saudi Human Genome Project (SHGP), one of the world's top ten genomics programs, depends on how Saudi society embraces the concept of genetic testing (Alrefaei et al., 2022).

### Study Justification

Saudi Arabia has a high burden of genetic diseases, mostly due to the high rate of marriage of relatives (around 50 to 60% of the marriages). The prevalence rate of consanguineous marriages was high compared with many other countries. The genetic diseases show up in the form of severe inherited diseases, which manifest early in life, affecting 8% of births in the kingdom, and in the form of common genetic diseases, such as diabetes, that manifest later in life and affect over 20% of the population. These diseases heavily impact quality of life for affected individuals and are a huge burden on the national health care system (IEEE Pulse, 2015; Al Husain and Al Bunyan, 1997).

The Saudi Genome Program is one of the most important and largest national projects in the Middle East. Besides, to reach the optimal objectives of this program, it is crucial to measure the knowledge of Saudi people about Saudi genome program and genetic testing and their attitude towards it.

### Specific objectives

To determine the knowledge of Saudi people about the Saudi genome program and genetic testing. To evaluate Saudi's attitudes toward Saudi genome program services.

## MATERIALS AND METHODS

### Study design and setting

A descriptive cross-sectional study was conducted in Al Ahsa, Saudi Arabia, using a non-probability convenience sampling technique.

### Data Collection Instrument and Method

Data was collected in November 2021. Participation is through an anonymous online survey. A web page link was distributed via social media such as WhatsApp, Twitter, and Facebook. The representative target sample size was needed to achieve the study objectives, and sufficient statistical power was calculated with a sample size calculator. The sample size was 369 participants, using a margin of error of  $\pm 5\%$ , a confidence level of 95%, a 40% prevalence of awareness regarding the Saudi genome program and genetic testing. In order to develop the questionnaire, the researchers reviewed many studies pertaining to the same topic or very close to it. The questionnaire was created, validated, and produced electronically in Google Forms. The questionnaire was evaluated by three consultants. To ensure an easy and wide reach, Google Forms was used to administer the online survey. Following participants' consent to complete the survey, they fill out a sequence of measures and demographic information.

Three sections comprised the survey questionnaire dispensed to collect data: 1) a brief explanation of the study and instructions for filling it out, 2) demographic information (age, gender, marital status, monthly income, level of education), and 3) 24 questions to identify the participants' knowledge, attitudes, and concerns about the genetic testing. All questions are mandatory. A 3-points likert scale was used for the third part. Responders specify their level of agreement to a statement typically in 3 points: 1-Agree, 2-Disagree, 3- Neutral.

### Ethical considerations

The Institutional Review Board (IRB) of the KFHH No. 13-EP-2021 approved this study in June 2021. A letter of informed participation, outlining the objectives and purposes of the study, was given along with the administered questionnaire. Participants were given the option to participate or not in this study. confidentiality agreement and an anonymity policy ensured that participants' privacy and confidentiality were protected.

### Data Management and Analysis

All obtained data was organized and analyzed by using the statistical package for social sciences (SPSS). This study used range (maximum and minimum), mean, and standard deviation to describe the data. Significance of the obtained results was judged at the 5% level.

## RESULTS

A total of 316 participants completed the survey, repre-

**Table 1.** Demographic Characteristics of the participants

Items	Frequency	Percent
<b>Age</b>		
20 or less	54	17.1
21-25	111	35.1
26-40	109	34.5
41 and more	42	13.3
<b>Education level</b>		
High school or less	73	23.1
University	215	68.0
Post graduate study	11	3.5
No formal education	17	5.4
<b>Marital status</b>		
Single	154	48.7
Married	162	51.3
<b>The monthly income for the family</b>		
High	39	12.3
Medium	250	79.1
Low	27	8.5
<b>Career</b>		
Has continuous work	88	27.8
No continuous work	228	72.2
<b>Do you have genetic diseases within your family?</b>		
No	251	79.4
Yes	65	20.6

senting (85.6%). The given table (1) represents the sociodemographic data of participants. As shown in table (1) 111 (35.1%) participants were in the 21-25 age group, while 109 (34.5%) participants were in the 26-40 age group. In terms of participants' educational levels, it appears that 215 (68%) of them were university graduates or students. In relation to marital status, 162 (51.3%) were married. The average monthly income of 250 (79.1%) was medium. Regarding employment status, 228 (72.2%) of the respondents had no continuous work. In terms of genetic diseases, 65 (20.6%) participants had genetic conditions.

Table (2) illustrates the knowledge about the Saudi genome program. The aim of the project is understood by 264 (83.5%) participants. About 212 (67.1%) participants agreed that genetic disease is something they are familiar with. In the study, 268 (84.8%) of respondents assumed that genetics is a field that focuses on the structure, function, and evolution of the genome, as well as genetic mapping and genetic editing. Only 106 (33.5%) of participants realized where genetic testing is performed. According to 208 (65.8%) of respondents, genetic disorders are common in their area. Among respondents, 136 (43 %) were able to define a genetic map.

Table (3) illustrates the practices and attitudes towards genetic testing. Near to two thirds of the participants, 200 (63.3%) had never undergone genetic testing before. In terms of the future attitude toward genetic testing, 226 (71.5%) expressed willingness to

undergo genetic testing. A majority of participants 259 (82%) agreed that genetic counseling was important. 175 (55.4%) respondents disagreed that genes banks are only for the wealthy. It was agreed by 235 (74.4%) participants that the project would reduce genetic and sexually transmitted diseases. 283 (89.6%) participants supported the idea of requiring all upcoming couples to undergo the genetic test. A total of 271 (85.8%) participants recommended not to marry if a test showed incompatibility. It was agreed by 280 participants (88.6%) that the results of the premarital test influence the decision to get married. A total of 274 (86.7%) participants agreed that genetic and infectious diseases negatively affect the psychological and economic well-being of the family. The majority of the participants 245 (77.5%) believed that beginning premarital education at age 15 is important.

Figure (1) displays the total knowledge score. There were more than half (56.3%) of the participants with high knowledge scores.

The figure (2) shows the total attitude score. The majority of participants 258 (81.6%) had a positive outlook towards genetic testing and genome program.

Table (4) illustrates the correlation between demographic data and total knowledge score. A positive correlation between age and knowledge could be clearly seen. There was also a relationship between having a genetic disease and knowing about it.

Table (5) shows how demographic data correlates with total attitude scores. The attitude toward the genome

**Table 2.** Knowledge about Saudi Genome Project

Items	Frequency	Percent
<b>The Saudi Genome Project is an initiative that aims to create an integrated information system that will help to prevent the spread of prevalent genetic disorders in Saudi society</b>		
Neutral	41	13.0
Agree	264	83.5
Disagree	11	3.5
<b>A genetic disease is something I am familiar with</b>		
Neutral	63	19.9
Agree	212	67.1
Disagree	41	13.0
<b>Genetics is one of the areas that focuses on the structure, function, and evolution of the genome, as well as genetic mapping and genetic editing</b>		
Neutral	44	13.9
Agree	268	84.8
Disagree	4	1.3
<b>I know what are the goals of the Saudi Genome Project</b>		
Neutral	84	26.6
Agree	152	48.1
Disagree	80	25.3
<b>the Saudi Genome Project's aim is to minimize genetic diseases</b>		
Neutral	29	9.2
Agree	275	87.0
Disagree	12	3.8
<b>I know where genetic testing is performed</b>		
Neutral	62	19.6
Agree	106	33.5
Disagree	148	46.8
<b>genetic disorders are common in my area</b>		
Agree	208	65.8
Disagree	33	10.4
Neutral	75	23.7
<b>I think there is a way to prevent the transmission of genetic diseases from parents to children</b>		
Agree	221	69.9
Disagree	27	8.5
Neutral	68	21.5
<b>we can detect diseases magnified through our genes only</b>		
Agree	198	62.7
Disagree	23	7.3
Neutral	95	30.1
<b>I know what the meaning of personalized medicine</b>		
Agree	126	39.9
Disagree	98	31.0
Neutral	92	29.1
<b>I know what a genetic map is</b>		
Agree	136	43
Disagree	106	33.5
Neutral	74	23.4
<b>I think my genes have an influence on my response to medication and treatment</b>		
Neutral	74	23.4
Agree	224	70.9
Disagree	18	5.7
<b>the Saudi genome program will improve the quality of life</b>		
Neutral	40	12.7
Agree	270	85.4
Disagree	6	1.9
<b>I know that there are tests other than the Premarital screening to identify genetic diseases</b>		
Neutral	42	13.3
Agree	237	75.0
Disagree	37	11.7

Table 3. Practices and Attitude towards Genetic Testing

<b>I have had genetic testing before</b>		
Neutral	43	13.6
Agree	73	23.1
Disagree	200	63.3
<b>I have a desire to conduct genetic tests in the future</b>		
Neutral	72	22.8
Agree	226	71.5
Disagree	18	5.7
<b>It is important to get genetic counseling</b>		
Neutral	50	15.8
Agree	259	82.0
Disagree	7	2.2
<b>Genes bank only for the rich people</b>		
Neutral	88	27.8
Agree	53	16.8
Disagree	175	55.4
<b>The project will reduce genetic and sexually transmitted diseases</b>		
Neutral	67	21.2
Agree	235	74.4
Disagree	14	4.4
<b>I support the idea of making all upcoming couples undergo the genetic test</b>		
Neutral	28	8.9
Agree	283	89.6
Disagree	5	1.6
<b>I recommend not marrying in case of incompatible test results</b>		
Neutral	36	11.4
Agree	271	85.8
Disagree	9	2.8
<b>The results of the premarital test influence the decision to get married</b>		
Neutral	30	9.5
Agree	280	88.6
Disagree	6	1.9
<b>Genetic and infectious diseases affect the family's psychological and economic well-being</b>		
Neutral	33	10.4
Agree	274	86.7
Disagree	9	2.8
<b>It is important to start premarital awareness at age 15</b>		
Neutral	56	17.7
Agree	245	77.5
Disagree	15	4.7

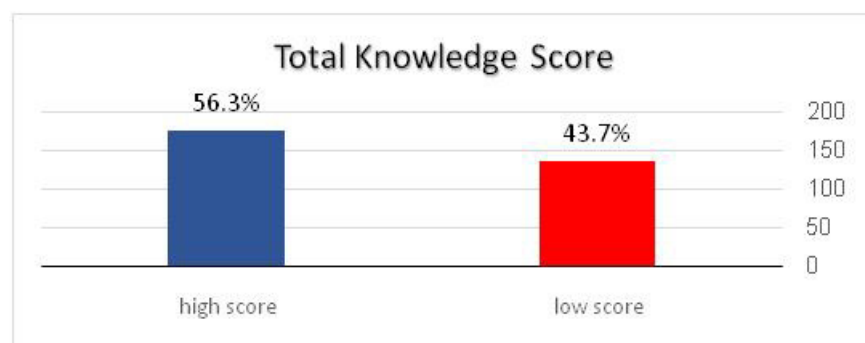
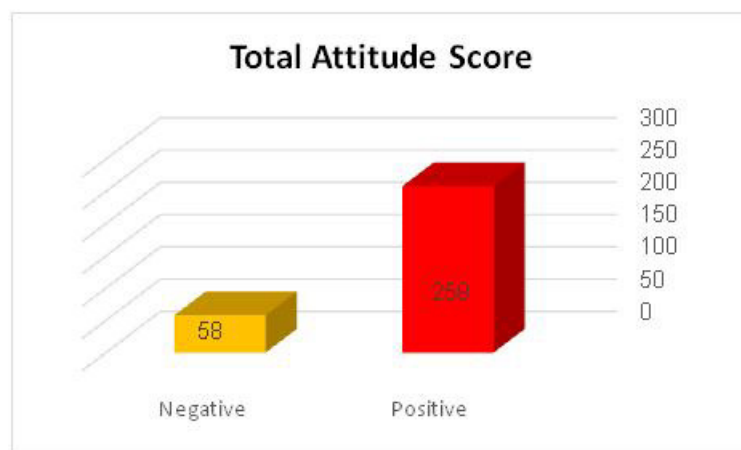


Figure 1. Total Knowledge score



**Figure 2.** Total Attitude Score

**Table 4.** Correlation between demographic data and total knowledge score

Demographic data and total knowledge score		
	Chi-Square	PV
Age	13.495 <sup>a</sup>	0.004
Educational level	3.944	0.268
Marital Status	1.160	0.281
Genetic diseases	6.937	0.008

**Table 5.** Correlation between demographic data and total attitude score

Demographic data and total attitude score		
	Chi-Square	PV
Age	12.215 <sup>a</sup>	0.007
Educational level	.535 <sup>a</sup>	0.911
Marital Status	2.779 <sup>a</sup>	0.095
Genetic diseases	4.546 <sup>a</sup>	.033

**Table 6.** Correlation between total knowledge score and total Attitude score

Knowledge score and total attitude score	
Chi-Square	PV
316.000 <sup>a</sup>	0.000

project and genetic testing were positively correlated with age of participants. It also correlates positively with marital status. Additionally, positively correlates with prior exposure to genetic disease.

Table (6) displays the correlation between total knowledge score and total attitude score. There was a significant positive correlation between attitude toward genome and genetic testing and knowledge score of participants.

## DISCUSSION

Having genetic diseases can have severe economic,

emotional, and physical effects on patients. Genetic diseases require patients to visit clinics more and stay longer in hospitals, which negatively impacts the healthcare system and economy (Miller et al., 2020; Gonzaludo et al., 2019). In this study, we measure the knowledge of the Saudi population about the Saudi genome program and genetic testing and their attitude towards it.

Our study found that nearly half of the participants (43.7%) had no prior adequate knowledge of the Saudi Health Genome Program (SHGP). We found similar results to a previous study done in Riyadh which found just (59.5%) of respondents were not aware of the SHGP (Alrefaei et al., 2022). The aim of the project is

understood by (83.5%) of participants. In a study performed in Riyadh, most participants (82.1%) understood that the SHGP aimed to document the first genetic map of Saudi citizens (Alrefaei et al., 2022). These results may be affected by the media and advertisements about the Saudi Genome Program goals.

In our study, (84.8%) of respondents assumed that genetics is a field that focuses on the structure, function, and evolution of the genome, as well as genetic mapping and genetic editing. Only (33.5%) of participants realized where genetic testing is performed. Its similar results with another study which found the survey respondents were very unaware of the available health services, which was unexpected (Alrefaei et al., 2021). These results can be attributed to the fact that asking about the genome appears to be more related to marriage and childbirth.

Near two-thirds of the participants (63.3%) had never undergone genetic testing before. In terms of the future attitude toward genetic testing, (71.5%) expressed willingness to undergo genetic testing. The results of our study revealed that the majority of participants (82%) agreed that genetic counseling was important. It was in the same line with another study which found that (63%) believed the tests should be required (Kelly and Farrimond, 2012). Public attitudes towards genetic testing for the risk of diseases have been found to be generally positive (Haga 2013; Henneman et al., 2013). Another study reported negative attitudes regarding discrimination, stigma, and confidentiality (Hann et al., 2017). The results for the acceptance and positive attitude toward genetic testing may be interpreted by the familiarity of the Saudi population with genetic diseases.

More than eight in ten participants (81.6%) were optimistic about genetic testing and the genome program. Similarly, another study reported that (87.2%) of participants had a positive attitude about the SHGP (Alrefaei et al., 2022). Jordanian study reported that at least (94%) of participants thought genetic screening was a good, comfortable, and reasonable procedure (Abdo et al., 2018). There is a possibility that these results can be attributed to the fact that many people have been affected by genetic diseases or heard about the effects genetic diseases have on families and communities.

According to our study, (10.4%) of participants supported not requiring the genetic test for future couples. A parallel study in Jordan found that (11.3%) of respondents believed that genetic testing is forbidden or not permissible, and (6.3%) disagreed with the idea of genetic testing in the future (Altaany et al., 2019). These results may be subsequent to conservative religious thoughts and concerns.

Along with the results of our study, a total of (85.8%) of participants recommended not to marry if a test showed incompatibility. It was agreed by (88.6%) that the results of the premarital test influence the decision to get married. A total of (86.7%) participants agreed that genetic and infectious diseases negatively affect the

psychological and economic well-being of the family. Similar results were reported in another study in Riyadh which reported that (85.6%) agreed to have genetic testing before marriage. This may be interpreted by increases in levels of education and literacy in Saudi Arabia about genetic testing and genetic diseases.

Education in medical genetics is particularly important in Arab countries (Altaany et al., 2019). Most of the participants (77.5%) believed that beginning premarital education at age 15 is important. A previous study reported that genetic disorders are common, and genetic literacy is generally low (Hamamy and Bittles, 2009).

Despite the benefits and applications of the genome program, the study found a lack of awareness about it. Nearly half of the participants (43.7%) scored low on total knowledge about the Saudi Genome Program. In the Riyadh study, (73.8%) of participants did not realize the benefits and applications of the SHGP (Arafah et al., 2021). Consequently, greater efforts are needed to educate people about the program and the human genome in general.

A positive correlation between age and knowledge could be seen. It is not in line with a study that found that the effect of status and age on awareness and attitude toward the SHGP was not statistically significant (Alrefaei et al., 2022). It may be interpreted that knowledge increased with age and experience.

16.8% of our survey respondents stated that this service is only available to the rich. In agreement with our findings, previous studies have reported that they are accessible only to the wealthier individuals, who represent nearly 20% of the population (Penchaszadeh, 2002; Christianson and Modell, 2004). These results may be interpreted by the need to explore more about the availability of the services and also clear information about the financial matters.

## CONCLUSION

In conclusion, this study delivers insight into the Saudi population's knowledge and attitudes regarding genetic testing and the Saudi Genome Program. Overall, the study found that attitudes towards genetic testing and the Saudi Genome Program were positive. Nevertheless, over half of the participants reported inadequate knowledge, which needs to be addressed in health education programs and media.

## Data Availability

The entire data set is available without restriction.

## Conflict of Interest

This study was conducted without any conflict of interest.

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