

## ORIGINAL RESEARCH ARTICLE

# Saudi Arabian women's knowledge and attitudes towards premarital screening of genetic disorders

DOI: 10.29063/ajrh2023/v27i12.8

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### Abstract

This study assessed the knowledge and attitudes of Saudi women regarding the premarital screening program (PMS) using a tailored questionnaire survey. Of the 185 participants, 176 (95.1%) were familiar with PMS, and 117 (63.2%) were aware of the diseases that the screening tests aim to detect. The majority of participants supported also including screenings for drug use and mental illness. When considering the situation of compatible partners with one being a carrier, a considerable proportion of respondents indicated they would not proceed with matrimony. Overall, the level of awareness and attitudes concerning the critical significance of PMS were deemed satisfactory. To mitigate the impact of diseases, it is imperative to continue disseminating information concerning the program, its importance, and the necessity of making well-informed decisions after the evaluations. (*Afr J Reprod Health* 2023; 27 [12]: 72-78).

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**Keywords:** Saudi Arabia, women, knowledge, attitudes, premarital screening

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### Résumé

Cette étude a évalué les connaissances et les attitudes des femmes saoudiennes concernant le programme de dépistage pré-nuptial (PMS) à l'aide d'un questionnaire personnalisé. Sur les 185 participants, 176 (95,1 %) connaissaient le syndrome prémenstruel et 117 (63,2 %) connaissaient les maladies que les tests de dépistage visent à détecter. La majorité des participants étaient également favorables à l'inclusion de dépistages de la consommation de drogues et de la maladie mentale. Lorsqu'on considère la situation des partenaires compatibles, dont l'un est porteur, une proportion considérable de personnes interrogées ont indiqué qu'elles ne procéderaient pas au mariage. Dans l'ensemble, le niveau de sensibilisation et les attitudes concernant l'importance critique du syndrome prémenstruel ont été jugés satisfaisants. Pour atténuer l'impact des maladies, il est impératif de continuer à diffuser des informations concernant le programme, son importance et la nécessité de prendre des décisions éclairées après les évaluations. (*Afr J Reprod Health* 2023; 27 [12]: 72-78).

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**Mots-clés:** Arabie Saoudite, femmes, connaissances, attitudes, dépistage pré-nuptial

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### Introduction

Pre-marital screening refers to a medical assessment carried out before marriage with the aim of identifying any potential health risks or genetic disorders that may impact the prospective couple<sup>1</sup>. Such screening has been implemented as a preventive strategy for identifying infectious diseases and hemoglobinopathies that are common in several Arab countries and are acknowledged as significant factors in mortality and morbidity worldwide<sup>2</sup>. In Saudi Arabia, hemoglobinopathies, namely sickle cell anemia and thalassemia, occur at significantly higher prevalence relative to neighboring countries<sup>3</sup>. The incidence of these diseases also displays significant regional variation

within the country, with the Eastern and Southern provinces having comparatively higher rates<sup>3,4</sup>. Furthermore, persistent escalation in the prevalence of certain hemoglobinopathies has been observed in southern Saudi Arabia despite the government's endeavors to curtail their incidence<sup>5</sup>. This elevated prevalence may be ascribed to consanguineous marriages<sup>5</sup>.

Saudi Arabia began implementation of a premarital screening program in 2001, which became mandatory in 2004<sup>3</sup>. Couples in the midst of making marriage arrangements are screened for the presence of hemoglobinopathies, namely sickle cell disease and thalassemia, along with infectious ailments such as HIV and hepatitis B and C<sup>6</sup>. The main objective of the program is to reduce the

probability of disease transmission to either partner or offspring<sup>6</sup>. In situations where partners are considered incompatible, engaged couples may choose to proceed with their marriage despite the possibility of adverse consequences<sup>7</sup>. The couples in question will be classified as "high-risk" and recommended to engage in counseling programs as a preventative measure<sup>7</sup>.

Being well-informed and having a positive attitude are believed crucial in disease prevention and control; as such, knowledge and attitudes among the Saudi population are matters of concern. A recent study with a significant sample size determined public awareness to be restricted concerning premarital screening programs and the associated tests<sup>6</sup>. Meanwhile, in a survey of unmarried male and female participants, Binshihon *et al.* found that while knowledge was lacking regarding premarital screening, attitudes toward it were positive<sup>8</sup>. Undoubtedly, enhancing knowledge and awareness of premarital screening will contribute to the promotion of a healthy marital lifestyle within the community<sup>1</sup>.

The current investigation focused on a cohort of adult female individuals, married and unmarried, and assessed their level of knowledge regarding the government-led premarital screening program in Saudi Arabia. It was anticipated that the collected data would demonstrate a change in the knowledge and attitudes of the participants toward the program. Where inadequate levels of awareness are observed, the educational component of the premarital screening program should be significantly enhanced for both Saudi and non-Saudi populations.

## Methods

### Study design

This cross-sectional study was conducted in Saudi Arabia, from March to May 2023. The questionnaire was devised and assessed by a member of the medical scientific community and researchers associated with the Department of Medical Laboratory Sciences at King Khalid University. The validated and pre-tested questionnaire was distributed randomly in Arabic, which was later translated into English for the purposes of better understanding and evaluation. The survey questions were distributed among

participants through an online Google Forms platform link that was sent to participants using different social media platforms. All Saudi and non-Saudi female individuals from all regions of Saudi Arabia and who accepted to take part in the study were included. The responses were collected in a manner that ensured anonymity and confidentiality. The participants were administered a detailed survey with the purpose of collecting data. The questionnaire commenced with a concise preamble outlining the investigation, namely its subject matter and goals. The survey included questions regarding participant nationality, age, geographic location, marital status, level of education, and employment history. The remainder of the survey comprised twenty questions divided into two distinct sections: the first section aimed to assess respondents' level of knowledge pertaining to premarital screening, while the second section aimed to elucidate their attitudes towards the matter. All participants were informed of the voluntary nature of their involvement and were given the option to withdraw at any moment at their discretion.

The sample size was calculated using Calculator.net, <https://www.calculator.net/sample-size-calculator.html>. A study by Al-Shroby *et al* assessed knowledge levels of PMS among Saudis and found that only 9.2% participants had satisfactory knowledge<sup>6</sup>. With a prevalence of 9.2%, a confidence level of 95%, and a 5% margin of error, the required sample size was estimated to be 129 participants.

### Data analysis

The responses of the participants were collected using the online Google Forms platform, and the data were analyzed using GraphPad Prism (version 9.00 for Mac, GraphPad Software, San Diego, CA). The sociodemographic characteristics of the participants were represented using descriptive statistics. The participants' knowledge and attitudes were quantified and represented as numbers and percentages.

### Ethical consideration

The study received approval from the research ethics committee at King Khalid University (HAPO-06-B-001), with the reference number ECM#2023-2201. The participants were provided

with information regarding the aim and questions of the study at the beginning of the questionnaire.

## Results

### *Socio-demographic characteristics*

Participants' nationalities, ages, locations (districts), marital statuses, levels of education, and occupations are all summarized in Table 1. A total of 185 responses were collected, with 180 (97.3%) representing Saudi women and only 5 (2.7%) representing non-Saudis. Participant ages ranged mostly from 20 to 30 years old. In terms of location, multiple regions of Saudi Arabia were represented; this geographic diversity enhanced the reliability and validity of the findings. One hundred and fourteen participants (61.6%) were married, and 71 (38.4%) unmarried. A range of educational levels were represented: 8 women (4.3%) held only a primary school degree, 13 (7%) an intermediate-level degree, and 41 a high school degree or equivalent (22.2%). The majority of respondents (n=116, 62.7%) had completed a bachelor's degree. Finally, 7 (3.8%) held advanced degrees. Regarding professional fields, only a small percentage of respondents (n=11, 5.9%) stated they worked in the medical field; the vast majority (n=174, 94.1%) expressed having no connection to the medical field.

### *Knowledge of the study participants toward the premarital screening program*

Greater knowledge is correlated with a favorable attitude and decreased prevalence of adverse health conditions. Here, participants were presented with a series of questions in order to evaluate their knowledge concerning premarital screening; the questions and responses are listed in Table 2. A significant majority of participants (n=176, 95.1%) demonstrated awareness of the premarital screening program. This suggests considerable familiarity with the program among the public.

Participants reported having learned about premarital screening via a number of sources, including friends and family, the Internet, social media, and television; these are also presented in Table 2. The single most common source was friends and family, consulted by 123 participants (66.5%). In addition, a substantial majority (n=174,

**Table 1:** Sociodemographic characteristics of the study participants (n=185)

Variable	n	(%)
<b>Nationality</b>		
Saudi	180	97.3
Non-Saudi	5	2.7
<b>Age (years)</b>		
< 20	3	1.6
20-30	104	56.2
31-40	46	24.9
> 40	32	17.3
<b>Region</b>		
Northern	4	2.2
Western	40	21.6
Eastern	9	4.9
Southern	120	64.9
Central	12	6.5
<b>Marital status</b>		
Married	114	61.6
Unmarried	71	38.4
<b>Level of education</b>		
Primary	8	4.3
Intermediate	13	7.0
Secondary	41	22.2
Undergraduate	116	62.7
Postgraduate	7	3.8
<b>Medical field</b>		
Yes	11	5.9
No	174	94.1

94.1%) were aware of the program's mandatory nature. Concerning the examinations included in the screening program, a total of 117 individuals (63.2%) demonstrated awareness of the targeted diseases. Overall, participants concurred with implementation of a premarital screening program and discouraging marriages between relatives as strategies to reduce the occurrence of certain diseases; however, they were not uniformly aware of the government's stance on incompatible marriages. A minority (n=49, 26.5%) expressed that the government permits weddings to occur even when a couple is deemed incompatible; the prevailing belief (n=89 participants, 48.1%) was that marriage is not allowed in such cases. Another quarter (n=47, 25.4%) exhibited uncertainty. Regarding the primary objective of the screening program, the consensus among participants was that it aimed to alleviate the burden that incompatible marriages impose on both the government and families (Table 2).

**Table 2:** Knowledge about the premarital screening program among the study population (n=185)

Variable	n	(%)
<b>Have you ever heard of the premarital screening program?</b>		
Yes	176	95.1
No	9	4.9
<b>From which source did you acquire information regarding the premarital screening program?</b>		
Relatives and friends	123	66.5
Internet	7	3.8
Television	7	3.8
Never heard of PMS	7	3.8
Social media	41	22.2
<b>Is the premarital screening program mandatory?</b>		
Yes	174	94.1
No	2	1.1
I don't know	9	4.9
<b>The premarital screening program encompasses</b>		
Sexually transmitted diseases	2	1.1
Hereditary diseases	39	22.1
Both	117	63.2
I don't know	27	14.6
<b>The objective of the premarital screening program is to reduce the transmission of certain diseases between spouses, form a healthy family, and produce healthy children.</b>		
Yes	179	96.8
No	1	0.5
I don't know	5	2.7
<b>The practice of consanguineous marriage elevates the likelihood of genetic disorders in progeny.</b>		
Yes	153	82.7
No	8	4.3
I don't know	24	13.0
<b>In Saudi Arabia, marriage is permitted even if the results of the premarital screening program are not compatible.</b>		
Yes	49	26.5
No	89	48.1
I don't know	47	25.4
<b>One of the goals of the premarital screening program is to alleviate the strain that incompatible marriages place on health institutions and blood banks.</b>		
Yes	93	50.3
No	14	7.6
I don't know	78	42.2

<b>One of the primary aims of the premarital screening program is to mitigate the occurrence of social and psychological issues within families that may arise when a child acquires diseases transferred by parents as a consequence of an incompatible marriage.</b>		
Yes	161	87
No	3	1.6
I don't know	21	11.4
<b>One of the goals of the premarital screening program is to lessen the financial burden of treating patients with diseases caused by incompatible marriages on families and society.</b>		
Yes	125	67.6
No	13	7.0
I don't know	47	25.4
<b>The sample employed by the premarital screening program is</b>		
Blood	170	91.9
Urine	0	0
I don't know	15	8.1
<b>The premarital screening program is applicable to</b>		
Male only	0	0
Female only	1	0.5
Both	184	99.5
<b>The hereditary transmission of genetic diseases results in the formation of unhealthy families and the birth of unhealthy children.</b>		
Yes	163	88.1
No	2	1.1
I don't know	20	10.8
<b>The premarital screening program determines the presence or absence of inherited blood diseases such as sickle cell anemia and thalassemia.</b>		
Yes	154	83.2
No	4	2.2
I don't know	27	14.6
<b>The premarital screening program involves</b>		
Hepatitis B virus	2	1.1
Hepatitis C virus	1	0.5
Hepatitis B and C virus	127	68.6
I don't know	55	29.7

Two questions concerned the specific spouse and sample tested in the premarital screening process (Table 2). Nearly all participants (n=184, 99.5%) were aware that testing is performed for both spouses. Additionally, 170 individuals (91.9%) were knowledgeable regarding the type of sample collected for screening. Finally, most participants demonstrated high awareness of the diseases covered in screening and the rationale for including them (that is, the potential consequences of incompatible marriages).

#### ***Attitudes of the study participants toward the premarital screening program***

Participants were further asked whether they would accept a spouse who carries a hereditary disease. Participants broadly agreed that continuing with a marriage despite incompatibility is the wrong decision, and a substantial number stated that they would not proceed with marriage if their partner was a carrier (Yes, n=39, 21.1%; No, n=98, 52.9%; I don't know, n=48, 25.9%). In addition, the survey

collected opinions on expanding the program, specifically to include mental health issues and drug abuse, which are current public health concerns. The majority of respondents expressed that screenings for mental illness (Yes, n=123, 66.5%; No, n=31, 16.8%; I don't know, n=31, 16.8%) and drug (Yes, n=153, 82.7%; No, n=7, 3.8%; I don't know, n=25, 13.5%) use should be incorporated. Finally, nearly all participants (Yes, n=178, 96.2%; No, n=1, 0.5%; I don't know, n=6, 3.2%) expressed the belief that knowledge of premarital screening contributes to the well-being of families and children.

## Discussion

The Saudi Arabian government has expressed concern regarding the growing prevalence of hereditary diseases throughout the country, and consequently established and enforced a premarital screening program to limit their spread, alleviate the burden that incompatible marriages impose on the government, and mitigate the incidence of social and psychological difficulties within families. Prior studies have evaluated the general Saudi population's awareness and comprehension of the premarital screening program. In the cultural milieu of Saudi Arabia, it is common for women to actively engage their guardians in the decision-making process for sake of greater sense of security and confidence in the outcomes of their choices. Hence, the present study aimed to specifically evaluate the autonomous and independent viewpoints of women in order to gain a more comprehensive insight into the female perspective concerning premarital screening.

The study population included both Saudi and non-Saudi participants of varying ages, representing locations throughout the country, and with differing marital status, level of education, and medical background. The diversity of this sample supports it being representative of public knowledge and attitudes.

Overall, participants expressed a gratifying level of awareness concerning the premarital screening program. A significant majority had been made aware mostly through word-of-mouth from their family and friends, and most were cognizant of the obligatory nature of the screening. This finding aligns with previous studies conducted in Saudi Arabia<sup>6-9</sup>. Additionally, a fair proportion of

participants were aware of the diseases and illnesses targeted by the program and the objectives behind its implementation. This observation likewise aligns with earlier reports and indicates reasonable awareness of the program among women<sup>6</sup>. When asked whether premarital screening should be expanded to include mental and drug screening examinations, a significant percentage of participants expressed approval of the idea. These

findings are also in alignment with prior studies<sup>9,10</sup>. In cases where a couple exhibits incompatible test results, it is customary for them to be referred to a counseling clinic for medical advice. As respondents were divided on whether the government would allow an incompatible couple to proceed with marriage, it is clearly important that this information be more efficiently disseminated.

As with the screening program in general, participants demonstrated substantial knowledge regarding the type of sample collected, the partner selected for testing, and the specific hereditary illnesses and viruses being screened for. However, recently published data indicates that the prevalence of hereditary illnesses remains very high<sup>5</sup>. This can be ascribed to couples persisting in their marriage despite incompatibility and in disregard of the medical advice supplied by counseling clinics. The present study further assessed participants' willingness to marry a compatible partner carrying a hereditary disease, and whether a marriage should proceed in the face of incompatibility. The responses were notably variable, consistent with the supposition that proceeding with marriage despite incompatibility underlies the continued persistence of inherited conditions<sup>5</sup>. However, participants also expressed a general agreement that disseminating information about the need for premarital screenings fosters the establishment of strong families and the birth of offspring with good health.

## Strengths, limitations, and public health implications

The completion of an official Saudi marriage is conditioned upon participating in a pre-marital screening program; however, in the event of incompatibility, program policy does not prohibit the continuation of the marriage. Hereditary blood diseases are prevalent in the country, and probably

the aforementioned policy is the main reason why these types of diseases have not decreased. The importance of this study lies in the fact that it assesses people's knowledge and attitudes toward the pre-marital screening program. Recognizing the misconceptions held by individuals highlights the importance of consistently providing public education on these concepts through diverse media channels.

## Conclusion

In conclusion, the findings indicate acceptable knowledge, awareness, and attitudes among participants. The variations seen in their responses underscore the need for increased education among the public, particularly women, regarding premarital screening. Furthermore, it is imperative to elucidate the reasons for the persistence of screened diseases despite the long-standing implementation of the program. As the participation of women is currently constrained, a bigger sample size is necessary to enhance the validity of the findings.

## Conflicts of interest

The authors declare no conflicts of interest.

## Acknowledgments

The authors extend their appreciation to the Deanship of Scientific Research at King Khalid University for funding this work through Small Group Research Project under grant number RGP1/223/44. We also would like to thank SERVICESCAPE ([www.servicescape.com](http://www.servicescape.com)) for the English language editing.

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