



## ASSESSING SAUDI ARABIAN INDIVIDUALS' ATTITUDES AND PERCEPTIONS ON THE CONFIDENTIALITY AND PRIVACY OF ELECTRONIC HEALTH AND MEDICAL INFORMATION

Anas Ali Alhur<sup>1\*</sup>, Afrah Ali Alhur<sup>2</sup>, Ebtehal Ali Baawadh<sup>3</sup>, Ahmed Khalufeh Alkhatami<sup>4</sup>, Maha ali sahli<sup>5</sup>, Zahra jaffar Ghaith<sup>6</sup>, Fay fahad alodail<sup>7</sup>, Asma Saeed Alghamdi<sup>8</sup>, Salma Mohammed Alghanoom<sup>9</sup>, Asrar Abdullah aljohani<sup>10</sup>, Ahmed Farhan Aldafiri<sup>11</sup>, Rihab Abdualh Ali<sup>12</sup>, Yusra Saleh Almoghams<sup>13</sup>, Khaled Abdul Rahman Al-Ghamdi<sup>14</sup>, Latifa Ahmed Binarafa<sup>15</sup>,

<sup>1\*</sup>College of Public Health and Health Informatics University of Hail, Hail, Saudi Arabia,  
Email: Anas.ali.alhur@gmail.com

<sup>2</sup>University of Hail, KSA, Email: afrahalhur@gmail.com

<sup>3</sup>Ministry of Health (MOH), Email: Ebtehal.ab96@gmail.com

<sup>4</sup>The Ministry of Health (MOH), KSA, Email: Pharmd.ahmed1@gmail.com

<sup>5</sup>Ministry of Health (MOH), KSA, Email: Mahasahli077@gmail.com

<sup>6</sup>Ministry of Health (MOH), KSA, Email: cute\_zozo35@hotmail.com

<sup>7</sup>Ministry of Health (MOH), KSA, Email: Fo.011@icloud.com

<sup>8</sup>Ministry of Health (MOH), KSA Email: Asma1alghamdi@outlook.com

<sup>9</sup>Ministry of Health (MOH), KSA, Email: salmasmoh@gmail.com

<sup>10</sup>Ministry of Health (MOH), KSA, Email: Asraralajohani@gmail.com

<sup>11</sup>Ministry of Health (MOH), KSA, Email: Ahmedaldafiri9@gmail.com

<sup>12</sup>Ministry of Health (MOH), KSA, Email: reahab2012@hotmail.com

<sup>13</sup>Ministry of Health (MOH), KSA, Email: yusra.moghamsy@gmail.com

<sup>14</sup>Ministry of Health (MOH), KSA, Email: Khaled\_alghamdi\_2012@hotmail.com

<sup>15</sup>Ministry of Health (MOH), KSA, Email: L.ahmed92@hotmail.com

**\*Corresponding Author:** Anas Ali Alhur  
Email: Anas.ali.alhur@gmail.com

### Abstract

**Introduction:** Health information privacy and confidentiality are essential for protecting personal health data in the digital age. Understanding individuals' perceptions of privacy is crucial for developing effective policies and technologies.

**Aim and Objective:** This study aimed to assess Saudi Arabian Individuals' Attitudes and Perceptions of the Confidentiality and Privacy of Electronic Health and Medical Information

**Materials and methods:** A descriptive cross-sectional design was employed, surveying 1034 Saudi Arabians aged 18 and above in 2023. The questionnaire consisted of 26 questions covering demographic information, awareness, and policies related to privacy and confidentiality.

**Results:** The survey revealed that approximately 43.5% of participants reported average computer skills. 4.1% experienced severe breaches of personal health information without consent. Additionally, 9.6% chose to forgo medical testing due to concerns about result confidentiality. 8.9% expressed discomfort with healthcare professionals using computers, and 13.6% had concerns about invading

personal information. Regarding awareness of their right to access and modify medical records, 29.1% were aware, 25.7% were unaware, and 45.3% were uncertain.

**Conclusions:** This research presents insight into Saudi nationals' views and understanding of health data privacy in the digital era. Analysis of responses from 1034 participants revealed nuanced attitudes regarding confidentiality and security of health information on online platforms. Our results could have lasting ramifications for shaping health policy within Saudi Arabia, particularly by emphasizing the need for robust strategies that protect personal health data, instilling greater trust and safety into digital healthcare systems used by users. Future research should address these findings by exploring larger samples, conducting longitudinal studies, and employing qualitative methods.

## INTRODUCTION

In today's rapidly evolving digital age, the exchange and accessibility of information have become effortless, bringing about numerous benefits to various industries, including healthcare. Electronic Medical Records (EMRs) and Electronic Health Records (EHRs) have emerged as transformative tools, revolutionizing the storage and management of patient information. However, one critical aspect demands unwavering attention and protection amidst their countless advantages: health information, privacy, and confidentiality. Health information privacy and confidentiality are fundamental aspects that form the bedrock of ethical medical practice, research, and the relationship between patients and healthcare providers. Safeguarding personal health data is crucial to protecting the rights and well-being of individuals, ensuring trust in healthcare systems, promoting effective healthcare delivery, and upholding ethical principles<sup>1-3</sup>.

EMRs, digital versions of traditional paper-based medical records, have revolutionized how patient data is recorded and accessible within healthcare settings<sup>4</sup>. Digital patient records offer a more efficient and accessible means of storing and retrieving patient information, eliminating the risk of misplacing records and decreasing physical storage needs. EMRs also ensure seamless information sharing among healthcare providers, giving all team members access to up-to-date patient records for efficient care delivery and coordination. EHRs expand upon the capabilities of EMRs by consolidating more comprehensive health-related information<sup>5</sup>. By compiling data from sources such as EMRs, laboratory results, radiology reports, and medication histories into one place, EHRs provide a holistic overview of patient health status. This holistic approach increases coordination among healthcare providers and improves patient outcomes<sup>6</sup>.

Furthermore, EMRs and EHRs create enormous data resources for analysis and research purposes<sup>7</sup>. Aggregated and de-identified data collected through these systems can be utilized for population health management, epidemiological studies, clinical research studies, and quality improvement initiatives<sup>8</sup>. Examining such information can uncover valuable trends, patterns, and insights that contribute to expanding medical knowledge and developing evidence-based practices<sup>9</sup>.

However, alongside the immense benefits, the collection and storage of patient data in EMRs and EHRs raise concerns regarding privacy, security, and data management<sup>10,11</sup>. Safeguarding personal health information becomes paramount to protecting individuals' rights, ensuring trust in healthcare systems, and maintaining the integrity of the patient-provider relationship<sup>12</sup>. Healthcare organizations and providers are responsible for implementing robust security measures and adhering to strict privacy regulations to prevent unauthorized access or breaches of patient information. Limited research exists on the attitudes and opinions of individuals in Saudi Arabia, specifically towards eHealth and the confidentiality and privacy of their medical information. Hence, the primary objectives of this research are as follows:

- 1- To assess the attitudes and opinions of Saudi Arabian individuals regarding the confidentiality and privacy of electronic health and medical information.

- 2- To identify participants' concerns and levels of trust regarding the confidentiality and privacy of health/medical information in computer-based environments.
- 3- To explore the level of trust of Saudi Arabian individuals regarding healthcare workers and researchers.
- 4- To examine participants' awareness of their rights and laws to access and modify their medical records.

By addressing these objectives, this research aims to contribute to understanding privacy and confidentiality issues in electronic health and medical information systems in Saudi Arabia, ultimately leading to improved privacy measures and enhanced patient experience.

## MATERIALS AND METHODS

A self-administered, anonymous, cross-sectional web-based study was conducted using an online questionnaire (Qualtrics®, Provo, Utah, United States) through a link shared via multiple social media platforms. The software encrypts the data using the Secure Sockets Layer (SSL) and maintains respondents' privacy by masking all respondents' Internet protocol (IP) addresses. Only the principal investigator could access the collected data through a password-protected portal. The study population was Saudi Arabians (1034), and those aged 18 and over were surveyed online using a questionnaire designed and validated by Özkan in 2011<sup>13</sup>. A total of 26 questions were included in the questionnaire regarding demographic information, focusing on attitudes and perceptions regarding electronic health and medical information.

The population is stratified based on demographic characteristics such as age, gender, education, and geographical region. The Sample size was determined using a confidence level of 95% and a margin of error of 5%. The calculation considered the estimated population size and the expected response rate. Participant recruitment was recruited through Google Forms, and a diverse range of participants was targeted to ensure representation from different age groups, genders, educational backgrounds, and geographical locations.

Ethics, guidelines, and procedures were strictly observed throughout this research project to protect participants' rights and privacy. Before their participation, informed consent was collected from all respondents detailing the purpose, voluntary participation, confidentiality of responses collected, and anonymization practices used during storage in accordance with ethical standards to maintain participant anonymity and data integrity.

## RESULTS

The study collected responses from 1034 participants, achieving an excellent response rate of 83.5%. Table 2 presents the demographic details, with most respondents being female (67.1%) and within the age group of 26-36 (39.6%). Notably, many respondents were pursuing or holding undergraduate degrees (62.7%), and half reported their health as excellent (49.8%). The reliability and internal consistency of the study variables were checked using Cronbach's alpha test. Scores were as follows: 0.873 for the perception of patient experience and concerns about health information privacy and confidentiality, 0.875 for trust levels of healthcare workers and researchers, and 0.846 for participants' awareness of laws and regulations about health and medical data in KSA. These satisfactory scores confirm the reliability of these variables for further analysis.

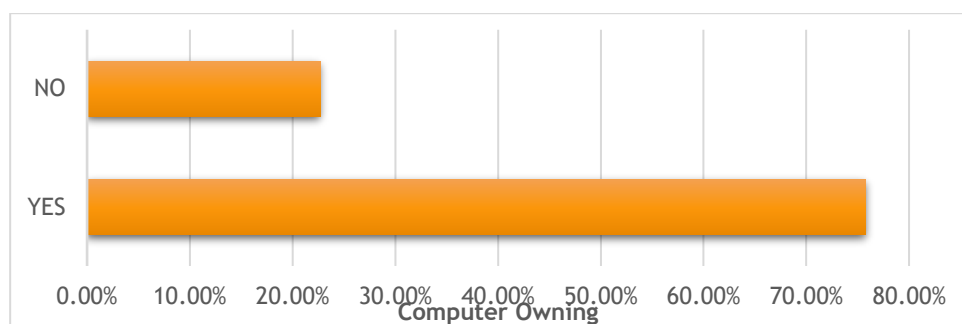
**Table 1:** The Coefficient Value of Cronbach's Alpha

No	Variables	Cronbach's Alpha	Number of Items
1	Perceptions	0.873	6
2	Experiences Concerns	0.875	6
3	Trust Levels	0.875	5
4	Awareness of Laws and Regulations	0.846	3

**Table 2: Demographic and Health Distribution**

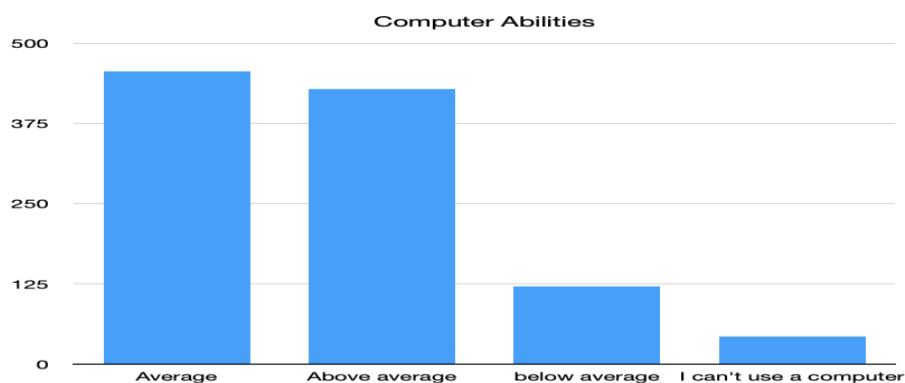
Category	Sub-Category	Percentage	Count
<b>Gender Distribution</b>	Male	31.2%	328
	Female	67.1%	706
<b>Age Distribution</b>	18-25	30.2%	318
	26-36	39.6%	417
	37-47	16.8%	173
	47 and above	11.7%	123
<b>Educational Level</b>	Middle and Primary school	3.5%	37
	High school	24.0%	252
	Undergraduate	62.7%	660
	Postgraduate	8.2%	86
<b>Health Status</b>	Very Poor	0.5%	5
	Fair	0.8%	8
	Good	10.8%	114
	Very Good	37.9%	394
	Excellent	49.8%	627

A substantial majority of 797 participants (75.8%) reported owning a computer, as seen below in Fig 1.



*Fig.1 Participants Computer Owning*

The survey results reveal a range of computer proficiency among respondents. 43.5% reported average computer skills, while 40.9% claimed above-average abilities; 15.5% of participants reported below-average or nonexistent computer abilities, highlighting the need for computer literacy initiatives within this segment.



*Fig.2 Assesses Participants' Computer Abilities.*

Table 3 thoroughly assesses patients' experiences and concerns about health information privacy and confidentiality. Most respondents (85.6%) have not experienced any serious violations of their personal health data, nor has any privacy concern prevented most respondents (76.8%) from seeking medical testing. Furthermore, 90.0 % have never asked doctors to alter their conditions' severity or embarrassing aspects in medical records.

**Table 3: Patient Experiences and Concerns About Health Information Privacy and Confidentiality**

Items (Concerns)	Yes	No	Don't know/Reject to answer	Mean	SD
Have you or a member of your family ever experienced a serious breach where your personal health information was used inappropriately or released without your consent?	43 (4.1%)	900 (85.6%)	101 (9.6%)	2.03	0.469
Have you ever decided not to be tested for medical conditions because you were concerned that others might find out about the results?	101 (9.6%)	808 (76.8%)	128 (12.2%)	2.01	0.3
Have you ever asked a doctor not to write down your health problem in your medical record, or asked the doctor to put a less serious or less embarrassing diagnosis into the record than was actually the condition?	41 (3.9%)	947 (90.0%)	53 (5.0%)	2.07	0.497

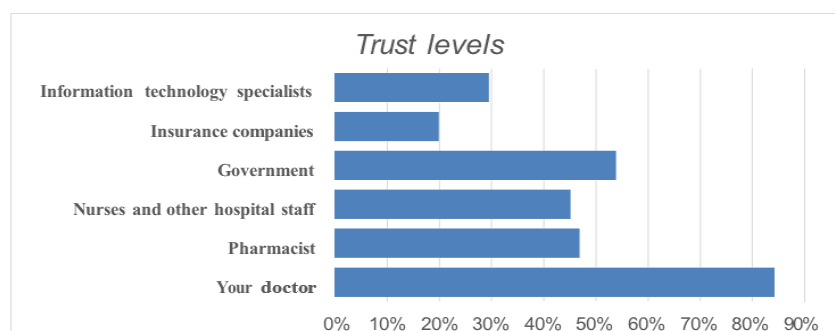
The following Table 4 summarizes respondents' comfort levels and concerns surrounding computer use in healthcare, the security of their personal health information, any perceived invasion of personal privacy, and potential threats to electronic medical records.

Responses to these items provide insight into various electronic health information privacy perspectives. While most respondents were comfortable with health professionals using computers for health information (74.0%), some perceptions indicated that their information was not secure (66%). Notably, authorized and unauthorized access (33.7%) are seen as threats to digital health privacy.

**Table 4: Respondents' Perceptions and Concerns Related to Electronic Health Information Privacy and Security**

Items (Concerns)	Yes	No	Don't know/Didn't think	Mean	SD
Do you feel uncomfortable with doctors and other health care professionals using computers to record and share personal health information within the health care system?	94 (8.9%)	779 (74.0%)	168 (16.0%)	1.59	0.867
In your opinion, is the health information which exists about you safe and secure?	694 (66%)	82 (7.8%)	265 (25.2%)	2.02	0.954
Are you concerned about the invasion of your personal information in KSA?	143 (13.6%)	730 (69.4%)	167 (15.9%)	2.61	1.119

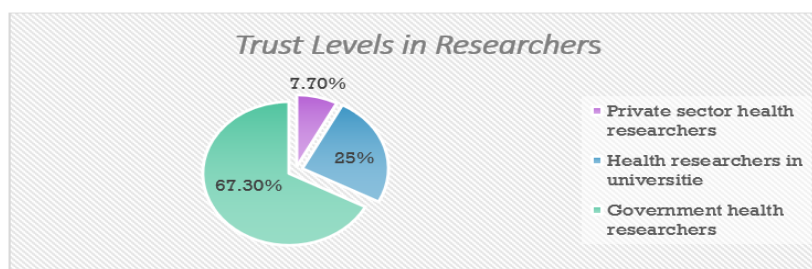
Based on responses, those expressing trust were most likely to trust their doctor, with 84% expressing it; pharmacists received moderate confidence, with 47.00% showing trust; nurses and hospital staff also demonstrated significant faith; the government earned 53.90% trust; insurance companies and IT specialists garnered significantly lower levels with 20% and 29.60%, respectively.



**Fig. 3 Trust levels of the participants in healthcare providers about the privacy of their medical information**

This survey sought to explore respondents' levels of trust toward different categories of health researchers. The results provided insight into participants' trust levels. Government health researchers were the most dependable group, garnering trust from an impressive 67.30% of the participants surveyed. University health researchers also earned respect; 25% of them placed their faith in them. Conversely, private-sector health researchers reached significantly lower levels of trust; only 7.70% of respondents expressed confidence in them. This indicates the different degrees of trust placed in various

sectors of health research - government researchers had the highest trust level, followed by university researchers and private sector researchers.



**Fig. 4** Trust Levels of the Participants in Researchers About the Privacy of Their Medical Information

Table 5 presents the respondents' awareness of laws and regulations pertaining to their medical records, data usage, and online access to medical data in the Kingdom of Saudi Arabia (KSA).

KSA individuals were not always aware of their legal rights and regulations for medical data in different ways, with only 29.1% understanding their right to access, modify, or delete medical records; 45.3% had little understanding. On the other hand, 57.5% knew about laws against unauthorized usage of patient information without consent, suggesting an understanding of data privacy regulations, while 59% knew how they could access records electronically, while 22.9% only had partial knowledge.

This result emphasizes the need for increased patient awareness and understanding of the legal aspects of medical data in Saudi Arabia. Effective communication and education strategies are critical in informing individuals of their rights as well as regulations governing their medical information, thus equipping individuals to protect it and make well-informed decisions regarding its usage and protection.

**Table 5:** Participants' Awareness of Laws and Regulations Pertaining to Health and Medical Data in KSA

Items (Questions)	Yes	No	Don't know	Mean	SD
As far as you know, do you have rights to reach your medical records and to demand modifying or deleting them in KSA?	402 (29.1%)	352 (25.7%)	462 (45.3%)	2.07	0.497
As far as you know, are there any laws in KSA which prevent your medical data from being used without your consent?	636 (57.5%)	145 (11%)	326 (31.4%)	1.59	0.867
As far as you know, are there any regulations in KSA which prohibit reaching medical data via the internet?	668 (59%)	274 (18%)	331 (22.9%)	2.02	0.546

## DISCUSSION

The finding that approximately half of the respondents, specifically 524 individuals (49.8%), indicated having excellent health is noteworthy. This suggests that a considerable proportion of the participants perceive their health status to be positive. It is important to consider the potential implications of this self-reported measure of health, as it relies on individuals' subjective assessments rather than objective medical evaluation. However, self-reported health status has been widely used in research studies and has been shown to be a valid indicator of overall health and well-being.

Moreover, we found that 797 individuals (75.8%) reported owning a computer, which consists of multiple studies conducted in the same population (KSA) of individuals<sup>14-18</sup>. According to the survey, a mere 4.1% of individuals have reported experiencing privacy breaches, while a majority of 85.6% have not. However, it has come to light that healthcare professionals in Denmark have publicly discussed confidential patient information, which is a clear breach of privacy and trust<sup>19</sup>. Preventive measures are crucial in order to limit future incidents. An individual's experiences regarding misuse or disclosure of their health data affect their perceptions of electronic health systems; those who have experienced breaches often remain cautious and dubious, while those who haven't experienced breaches view these systems as more reliable and secure.

Privacy concerns affect medical participation. Healthcare providers must ensure the secure handling of health data and address breaches promptly. In our study, 3.9% of participants preferred limiting their health problems in records. This contrasts with Moerenhout et al.'s (2021) findings, where

participants were more likely to withhold current (25%) than past information (37.5%) from physicians<sup>20</sup>.

8.9% of the survey participants expressed concerns about doctors using computers for their health information, indicating potential worries about safety and unauthorized access. In a previous study, 32.91% of respondents (1275 patients) had privacy concerns<sup>21</sup>. To address these concerns, healthcare providers and policymakers must prioritize building trust with patients and ensuring their health data is kept secure. Patients should feel at ease when using 12 electronic health systems, and any privacy breaches need to be handled promptly and with great care.

Protecting patient trust and confidentiality is crucial when using electronic health systems. Healthcare providers and policymakers must address patients' privacy concerns, as some still express reservations. It's essential to take necessary measures to protect health data and establish trust. A US survey found that 54-59% of participants were highly concerned about health information privacy<sup>22</sup>. Furthermore, a study conducted in 2022 indicated that many participants expressed strong confidence in the healthcare system's ability to protect electronic patient information<sup>23</sup>.

Our research findings demonstrate a high level of trust in participants' doctors, as indicated by most participants. Trust in doctors may stem from their expertise, experience, and the personal relationships they build with patients over time<sup>24-26</sup>. This high level of trust in doctors reflects individuals' confidence in their healthcare providers to deliver quality care, provide accurate diagnoses, and maintain the confidentiality of their health information<sup>25,27-29</sup>. The survey results indicated that a considerable percentage of participants, 67.30% expressed trust in government health researchers<sup>30</sup><sup>32</sup>.

This finding shows a high level of confidence in the work conducted by these researchers. It suggests that the public perceives government health researchers as reliable and trustworthy in addressing health-related concerns and providing accurate information. This level of trust is crucial for maintaining public confidence in the research conducted by government institutions and reinforces the importance of transparency and credibility in health research. This trust may be attributed to the perception that credible institutions support government health researchers, have access to ample resources, and follow strict scientific standards.

Nearly one-third of participants were aware of their rights concerning accessing and modifying their health information. This knowledge indicates understanding the relevant laws and regulations that grant individuals these rights. It is crucial to continue promoting awareness and transparency in healthcare systems to empower individuals in managing their health information. A lower percentage of research conducted in a developing country found that only 9% of patients knew the regulations about their rights as patients<sup>33</sup>.

According to the survey results, most participants, 59%, demonstrated awareness of the regulations. This suggests that a considerable portion of individuals recognize the importance of protecting medical data and are familiar with the regulations prohibiting unauthorized access through the Internet. This awareness reflects the efforts made by regulatory bodies and healthcare organizations to educate the public about the potential risks and legal consequences of unauthorized access to medical information online.

## CONCLUSION

This research conducted in Saudi Arabia (KSA) provides insight into how people interpret and perceive the privacy and confidentiality of health data in digital platforms (HER/EMR). Studies in this field within KSA are relatively scarce, making it even more imperative that attitudes and opinions specific to Saudi culture be explored thoroughly. The survey findings indicated that approximately 43.5% of respondents reported average computer usage. Concerning personal health information breaches, 4.1% of participants reported experiencing a severe breach where their health information was used or released without consent. Furthermore, 9.6% of respondents admitted to forgoing medical testing due to concerns about the confidentiality of the results. Regarding the use of computers by healthcare professionals to record and share personal health information, 8.9% of participants expressed discomfort, and 13.6% had concerns about the invasion of personal information. Regarding

their right to access and request modifications or deletions in their medical records in KSA, 29.1% of participants were aware, 25.7% were unaware, and 45.3% were uncertain.

Several recommendations for future research are proposed to address these limitations and deepen our understanding of the topic. These include conducting extensive investigations with larger and more diverse samples, implementing longitudinal studies to track changes over time, incorporating qualitative research methods for deeper insights, conducting comparative studies across different countries, examining the impact of technological advancements, and analyzing existing policies and regulations for potential improvements. By following these recommendations, future research can contribute to a more comprehensive understanding of privacy and confidentiality issues in healthcare, particularly in Saudi Arabia.

Although this study makes significant strides toward understanding privacy and confidentiality concerns in electronic health and medical information systems in Saudi Arabia and its potential to enhance privacy measures and patient experience, it has some notable limitations. These include sample size and its representativeness issues; the cross-sectional design; self-reported data usage; using only one research instrument; and limited scope/timeframe for data collection.

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## Appendix 1

- ***Your participation in this study is voluntary, and you may choose not to participate or end your participation at any time without penalty. Do you agree to participate?***
  1. *Agree*
  2. *Disagree*

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### ***Demographic information***

- ***Gender***
    1. *Male*
    2. *Female*
  - ***Age***
    1. *18-25*
    2. *26-36*
    3. *37-47*
    4. *47 and above*
  - ***Educational Level***
    1. *Middle and Primary school*
    2. *High school*
    3. *Undergraduate*
    4. *Postgraduate*
  - ***Health Status***
    1. *Very Poor*
    2. *Fair*
    3. *Good*
    4. *Very good*
    5. *Excellent*
- 
- ***Do you have a computer?***
    1. *Yes, I do*
    2. *No, I do not*
  - ***What is your computer skill level?***
    1. *I can't use a computer*
    2. *Below average*
    3. *Moderately familiar*
    4. *Average*
    5. *Above average*
  - ***Have you or a member of your family ever experienced a serious breach where your personal health information was used inappropriately or released without your consent***
    1. *Yes*
    2. *No*
    3. *Don't know/Reject to answer*
  - ***Have you ever decided not to be tested for medical conditions because you were concerned that others might find out about the results?***
    1. *Yes*
    2. *No*
    3. *Don't know/Reject to answer*

- ***Have you ever asked a doctor not to write down your health problem in your medical record or asked the doctor to put a less serious or less embarrassing diagnosis into the record than was actually the condition?***
    1. *Yes*
    2. *No*
    3. *Don't know/Reject to answer*
  
  - ***Do you feel uncomfortable with doctors and other health care professionals using computers to record and share personal health information within the health care system?***
    1. *Yes*
    2. *No*
    3. *Don't know/Reject to answer*
  
  - ***In your opinion, is the health information that exists about you safe and secure?***
    1. *Yes*
    2. *No*
    3. *Don't know/Reject to answer*
  
  - ***Are you concerned about the invasion of your personal information in KSA?***
    1. *Yes*
    2. *No*
    3. *Don't know/Reject to answer*
  
  - ***What is your trust level in healthcare providers about the privacy of their medical information?***
    1. *Information technology specialists*
    2. *Insurance companies Government*
    3. *Nurses and other hospital staff*
    4. *Pharmacist*
    5. *Your doctor*
  
  - ***What is your trust level in researchers about the privacy of their medical information?***
    1. *Private-sector health researchers*
    2. *Health researchers in universities*
    3. *Government health researchers*
  
  - ***As far as you know, do you have the right to reach your medical records and to demand modifying or deleting them in KSA?***
    1. *Yes*
    2. *No*
    3. *Don't know/Reject to answer*
  
  - ***As far as you know, are there any laws in KSA that prevent your medical data from being used without your consent?***
    1. *Yes*
    2. *No*
    3. *Don't know/Reject to answer*
  
  - ***As far as you know, are there any regulations in KSA that prohibit reaching medical data via the Internet?***
    1. *Yes*
    2. *No*
    3. *Don't know/Reject to answer*
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***Thank you for completing the survey! We appreciate your time and effort in providing us with your valuable response.***