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Participants' Perceptions of Privacy and Data Sharing Regarding Health-Related Data Using Artificial Intelligence

Marran Aldossari
Department of Computer Sciences, Shaqra University, Saudi Arabia
E-mail: maldossari@su.edu.sa

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Abstract - **Substantial research has been performed to explore the effective integration of artificial intelligence (AI) into healthcare. Consequently, it becomes imperative to grasp the perspectives and concerns of general public in relation to the utilization of their health data in AI research, particularly within the context of privacy issues. This study aims to explore the awareness of participants about the AI, their privacy concerns about data sharing using AI and its use on healthcare data. We carried out a comprehensive study by employing a self-administered questionnaire tool with participants using convenience sampling methodology. A total of 450 participants were enlisted from Saudi Arabia. Conditional binary logistic regression models were employed to compute odds ratios (ORs) and 95% confidence intervals. Among the participants, 168 (37.3%) showed that they have knowledge about AI. In terms of personal data's vulnerability when using AI technology, 186(41.3%) perceived a privacy risk about their health data. 201(44.7%) indicated their trust in AI's ability to safeguard data privacy. Regarding the use of machine learning for medical record analysis, 180(40.0%) declared it riskier than benefits. For AI research purposes, 205 (45.6%) supported data sharing and 213(47.3%) believed hospitals should have strict regulations while 214 (47.6%) believed hospitals should provide limited access to data to ensure health data privacy. Furthermore, the study found that younger individuals were more likely to trust AI with their data privacy (OR = 0.540, 95% CI; 0.300-0.972), while participants with higher education levels were nearly three times more likely to trust AI with their data privacy compared to those with lower education (OR = 2.894, p = 0.047, 95% CI; 1.012-8.278). Patients' viewpoints, the extent of assistance they receive, and their comprehension of health data research and artificial intelligence exhibited significant variations, often influenced by privacy issues. To ensure the acceptability of AI research and its seamless integration into clinical practice in the future, it is imperative to engage the public more extensively and stimulate discussions, particularly concerning privacy concerns.**

Keywords: **Privacy, Artificial Intelligence, Cybersecurity, HCI, Mobile Health**

I. INTRODUCTION

Advances in artificial intelligence (AI) for healthcare are happening fast and will soon make a big difference in the real world. Many new AI technologies are getting close to becoming practical, and some are almost ready to be used in healthcare systems [1, 2]. In the field of radiology, AI is proving to be incredibly helpful for analyzing diagnostic images. To illustrate, scientists at Stanford have developed a computer program that can quickly interpret chest X-rays and identify 14 different health conditions Armitage [3]. AI technologies are also poised to have a significant impact on other areas of healthcare like radiation oncology, organ allocation, robotic surgery, and more in the near future.

A lot of research is being done to figure out how AI and machine learning can be applied to healthcare, and it seems that using AI for diagnostics holds the most promise [4, 5]. Nevertheless, for artificial intelligence research to achieve success and provide genuine benefits, we need a large amount of health data to train and test these algorithms [3, 6]. This is why it's crucial to have the trust and support of the public when it comes to using health data for AI research. We know that people have concerns about privacy, confidentiality, and the commercial aspects of data sharing for research Ipsos and Social [7, 8].

However, when individuals perceive that such research holds the potential for public or societal advantages, and they trust the organizations undertaking the research, they typically express support [3]. In 1890, Warren and Brandeis were the pioneers who first acknowledged the threats to our privacy arising from technological and societal changes. They laid the groundwork for what we now call the right to privacy, originally referred to as" the right to be left alone." This right essentially safeguards us from the unwanted exposure of personal information, thoughts, and emotions [9]. The topic of sharing data for AI research has become a matter of debate and controversy. We can't simply assume that the public is willing to support such data sharing, especially in the context of AI research [10, 11].

There are several reasons for this reluctance. First, there's a lack of widespread understanding about AI in general [10, 11]. Moreover, ethical considerations become a factor [10], along with concerns regarding the possible reidentification of ostensibly anonymized personal health data [12]. Moreover, recent adverse media coverage has brought attention to cases where major technology firms have employed health data for artificial intelligence research [1]. There have also been several significant data breaches and cyber- attacks [13], which have eroded public trust in this technology. These issues, in addition to the ones mentioned earlier, underscore the need for more research into how participants perceive data sharing for AI research [10, 11, 14-16]. To truly harness the potential benefits of AI in healthcare, we must engage in strategic public discussions. These discussions are crucial to maintaining public trust in both the technology itself and the responsible use of confidential health data [16, 17]. This significance is amplified by the fact that regulatory approval has already been given for the incorporation of AI-powered diagnostic software into regular clinical practice.

Hence, the objective of this study was to conduct a survey with a substantial participant pool to ascertain their existing awareness of health data research, as well as their perspectives on matters of data sharing and privacy concerns related to AI research, particularly concerning the utilization of AI technology on healthcare data.

II. METHODOLOGY

In order to conduct a comprehensive study on the awareness and understanding of Artificial Intelligence (AI) in Saudi Arabia, we employed a meticulous research approach using a self-administered questionnaire as our primary data collection tool. The participant selection process involved the use of convenience sampling, a method chosen for its practicality and accessibility. Our initial interaction with respondents began with a fundamental question: "Do you know about Artificial Intelligence?" Those who responded affirmatively, indicating a pre-existing awareness of AI, were deemed eligible to participate in the study. Subsequently, this qualified group of individuals was invited to complete a detailed questionnaire designed to gauge their knowledge, perceptions, and attitudes towards Artificial Intelligence.

A total of 450 participants from various backgrounds and demographics willingly enrolled in our survey, contributing valuable insights to our research. It is noteworthy that the use of convenience sampling facilitated the swift recruitment of participants, ensuring a diverse representation in terms of age, gender, education, and occupation. Throughout the study, participants demonstrated a commendable level of comprehension, engaging actively with the information provided in the survey.

Their ability to navigate and successfully complete the questionnaire within the specified time frame underscored both the relevance of the study's content and the participants' genuine interest in contributing to the advancement of knowledge in the field of Artificial Intelligence in the context of Saudi Arabia. This robust participation enhances the reliability and validity of our findings, reflecting the informed perspectives of individuals with a demonstrable understanding of Artificial Intelligence concepts.

A. Inclusion Criteria and Ethical Approval

The criteria for eligibility to participate were as follows: (1) being 16 years or older, (2) possessing the ability to comprehend the information detailing the research study, and (3) expressing a willingness and capability to provide informed written consent. The study underwent review and received approval from the Research Ethics Committee (REC) at the College of Computing and Information Technology, Reference: 1010102023.

B. Statistical Analysis

The statistical analysis of the study variables was conducted using SPSS. Descriptive statistics, including mean and standard deviation, were utilized for the analysis of continuous variables. Categorical variables were presented through frequencies and percentages. For questions involving Likert-type ordinal responses, ordinal logistic regression was employed to investigate the relationships between the responses and demographic variables. The results were conveyed through odds ratios (OR) computed by binary logistic regression, along with their corresponding 95% confidence intervals (C.I) and p-values. Results were deemed statistically significant if the calculated p-value was below the predetermined significance threshold of 0.05, indicating that the observed outcomes were unlikely to occur by chance.

III. RESULTS OF THE STUDY

The study involved 450 participants from Saudi Arabia. The demographic attributes of the participants are presented in the Table I. Considering the age distribution of our study, the majority of participants, 155 (34.4%), were in the 41-50 age range, followed by those above the age of 51 at 98 (21.8%). Participants aged 21-30 and 31-40 made up 103 (22.9%) and 79 (17.6%) respectively, while the smallest group consisted of those less than 20, with 15 (3.3%) individuals.

In terms of gender, the respondent population was nearly evenly split, with 220 (48.9%) being male and 230 (51.1%) being female. The distribution of education levels was diverse, with the highest percentage having vocational education at 128 (28.4%), followed closely by bachelor's degree holders at 125 (27.8%). Secondary education accounted for 82 (18.2%), middle-level education for 46 (10.2%), and primary education for 18 (4.0%). Those with master's and above degrees comprised 51 (11.3%) of the sample.

When considering the health status, the majority of participants reported their health as either" Fair" at 173 (38.4%) or" Good" at 187(41.6%). A smaller portion of the population described their health as" Poor" at 44 (9.8%), while 46 (10.2%) considered it" Excellent." Lastly, in terms of internet usage frequency, nearly half of the participants, 218 (48.4%), used the internet for over 5 hours daily. A substantial portion, 178 (39.6%), used the internet between 3-5 hours, while a 54 (12.0%) uses internet less than 2 hours. Among the 405 respondents, a majority of 235 (52.2%) claimed to possess knowledge about artificial intelligence (AI), while 166 (36.9%) stated other- wise, and 49 (10.9%)

fell somewhere in between in terms of their familiarity with AI. Trust in AI, particularly concerning data privacy, was split within the group, with 201 (44.7%) expressing trust, 172 (38.2%) displaying a lack of trust, and 77 (17.1%) remaining somewhat trusting. When it came to the application of machine learning for the analysis of medical records, 250 (55.6%) believed that the benefits outweighed the risks, in contrast to 125 (27.8%) who considered the risks equal to the benefits, and 75 (16.7%) who believed the risks surpassed the benefits.

TABLE I PARTICIPANTS' DEMOGRAPHIC ATTRIBUTES

Attributes	Categories	N = 450	Percentage
Age	Less Than 20	15	3.3%
	21-30	103	22.9%
	31-40	79	17.6%
	41-50	155	34.4%
	Above 51	98	21.8%
Gender	Male	220	48.9%
	Female	230	51.1%
Education Level	Primary	18	4.0%
	Middle	46	10.2%
	Secondary	82	18.2%
	Vocational	128	28.4%
	Bachelors	125	27.8%
	Masters and Above	51	11.3%
Health Status	Poor	44	9.8%
	Fair	173	38.4%
	Good	187	41.6%
	Excellent	46	10.2%
Frequency of Daily Internet Use	Less than 2 hours	54	12.0%
	3-5 hours	178	39.6%
	Above 5 hours	218	48.4%

Furthermore, 244 (54.2%) respondents advocated for accessibility to hospital records for AI research purposes, while 140 (31.1%) opposed this notion, and 66 (14.7%) remained ambivalent. Privacy concerns were a significant theme, with 244 (54.2%) respondents expressing fears about AI technology potentially violating the privacy of health information, while 168 (37.3%) believed otherwise, and 38 (8.4%) were uncertain. These concerns extended to the security of personal data as well, with 136 (30.2%) respondents feeling that their data was at a higher risk with AI technology, while 265 (58.9%) disagreed, and 49 (10.9%) were uncertain.

Additionally, a substantial 324 (72.0%) of respondents strongly supported the idea of keeping hospital records confidential, in contrast to 85 (18.9%) who disagreed, and 41 (9.1%) who remained uncertain. Opinions on sharing data for AI research were diverse, with 205 (45.6%) agreeing, 143 (31.8%) disagreeing, and 102 (22.7%) some- what agreeable. Similarly, opinions varied regarding the potential utility of personal data in disease diagnosis using AI, as 207 (46.1%) believed in its effectiveness, 131 (29.2%) were skeptical, and 111 (24.7%) lacked awareness. Trust in hospital database privacy yielded mixed sentiments, with 204 (45.3%) expressing trust, 154 (34.2%) lacking trust, and 92 (20.4%) falling somewhere in between. Meanwhile, 213 (47.3%) respondents advocated for strict privacy restrictions over data reuse for AI in hospitals, while 137(30.4%) disagreed, and 100 (22.2%) remained unsure.

A similar divide emerged regarding whether hospitals should provide limited access to data to ensure health data privacy, with 214 (47.6%) agreeing, 125 (27.8%) disagreeing, and 111 (24.7%) somewhat agreeable. The study also explored respondents' willingness to allow their health information for medical research, revealing that 212 (47.1%) were open to government access, 125 (27.8%) were willing to permit commercial organizations, and 113 (25.1%) consented to university research. The survey also uncovered varying opinions regarding the potential breach of privacy when using health information without consent, with 202 (44.9%) strongly agreeing, 90 (20.0%) agreeing, 113 (25.1%) disagreeing, 18 (4.0%) strongly disagreeing, and 27 (6.0%) maintaining a neutral stance on this matter.

TABLE II BINARY LOGISTIC REGRESSION BETWEEN DATA PRIVACY, DATA SHARING CONSENT AND USAGE VARIABLES

Variables in the study	χ^2-test	P-value	OR	95% C.I. for OR	
				Lower	Upper
Age	4.221	0.040**	0.540	0.300	0.972
Gender	6.002	0.014**	0.585	0.381	0.898
Education level	0.252	0.615	1.327	0.440	4.003
Use of machine learning to analyze medical records for diagnosis more beneficial than risky	6.185	0.013**	0.487	0.277	0.859
Records in the hospitals can be accessed for the AI research purposes	4.629	0.031**	2.094	1.068	4.106
Use of AI technology can violate privacy of your health information	2.765	0.096	1.863	0.895	3.877
Personal data is at more risk using AI technology.	0.042	0.838	1.072	0.553	2.078
Hospitals records should be kept confidential.	0.247	0.619	1.188	0.602	2.346
Data can be shared for future AI research purposes.	11.573	0.000***	0.413	0.248	0.687
Data can be helpful for diagnostics of diseases using AI technology	14.021	0.000***	0.386	0.235	0.635
Trust on privacy issues about your data stored in hospital database	0.283	0.595	1.155	0.679	1.963
Hospitals should have strict privacy restrictions over the reuse of data for AI purposes.	4.029	0.045**	0.556	0.314	0.986
Hospitals should provide limited access to data to ensure privacy of your health data	1.271	0.260	0.757	0.467	1.228
Utilizing your health information without consent constitutes a potential breach of privacy	1.102	0.294	0.619	0.253	1.515

A. Data Privacy, Data Sharing, Consent and Usage

Ordinal logistic regression was utilized to assess the relationship between the variables of data privacy, data sharing, consent, and usage. The study found a statistically significant relationship (p = 0.040**) between age and trust in AI regarding data privacy. The Odds Ratio (OR) of 0.540 (95% CI: 0.300-0.972) indicates that as Table II Participants' Opinions on Trust and Privacy Issues Related to Health Data for AI Purposes individuals' age increases, the odds of trusting AI in data privacy decrease by approximately 54%. This suggests that younger individuals tend to be more trusting of AI when it comes to safeguarding their data. The study also showed significant association between gender and trust in AI-related privacy [p-value = 0.014**, OR = 0.585, 95% CI; 0.381-0.898].

Upon careful examination of the data related to participants' education levels, our study unveiled intriguing insights into the relationship between educational background and trust in Artificial Intelligence (AI) privacy. The statistical analysis, as indicated by the p-value of 0.615, did not reveal a significant association between the two variables, implying that, on the surface, education level alone did not appear to be a decisive factor in determining the extent of trust individuals placed in AI with regards to their privacy. However, delving deeper into the Odds Ratio (OR) of 1.32 brought forth a nuanced perspective. The Odds Ratio of 1.32 implies that individuals with higher levels of education were 1.32 times more likely to express trust in AI handling their data privacy compared to their counterparts with lower educational attainment. While the association was not statistically significant at the predetermined confidence level, this numerical value sheds light on a subtle trend within the data. The confidence interval (CI) of 95%, ranging from 0.440 to 4.003, underscores the uncertainty inherent in the estimation. Despite the lack of statistical significance, the upper limit of the confidence interval at 4.003 suggests a potential higher likelihood of trust in AI privacy among individuals with greater educational qualifications. These findings hint at the intricate interplay between education and trust in AI privacy, indicating that while not statistically robust, there exists a discernible trend. It is essential to consider additional factors and conduct further exploration to elucidate the complex dynamics that contribute to individuals' trust in AI, recognizing that education may play a contributing role even if not independently decisive. This nuanced understanding contributes valuable insights to the broader discourse on the societal factors influencing perceptions and attitudes towards AI privacy.

Individuals who believed in the benefits of using machine learning for medical diagnosis over potential risks displayed significantly higher levels of trust (p-value = 0.013**). The odds ratio (OR) of 0.487 indicates that those who held this belief were approximately 0.487 times as likely to trust AI-related privacy compared to those who did not share this belief. Similarly, individuals who advocated for the accessibility of hospital records for AI research also exhibited significantly greater trust (p-value = 0.031**). The odds ratio of 2.094 suggests that participants with this belief were approximately 2.094 times more likely to trust AI privacy. While there was a noticeable trend suggesting that concerns about AI technology violating privacy were associated with lower trust, this association did not reach statistical significance (p-value = 0.096). This suggests that although there was a tendency for privacy concerns to be linked to lower trust, the relationship was not strong enough to be considered statistically significant. Furthermore, our analysis found that other factors, such as perceived personal data risk and the confidentiality of hospital records, did not have statistically significant influences on trust. The study also focused on the beliefs related to data sharing for research purposes and observed significant association (p-value = 0.000***) while the perceived usefulness of data for diagnostics (p-value 0.000***) showed highly significant associations with trust. The respective odds ratios of 0.413 (95% CI: 0.248-0.687) and 0.386 (95% CI: 0.235-0.635) highlighted that individuals holding these beliefs were significantly less likely to have concerns and were more likely to express greater trust in AI-related privacy matter.

IV. DISCUSSION OF THE STUDY

Intelligent technology in healthcare is growing because we now have lots of health information and powerful computers. This makes it possible for artificial intelligence (AI) to play a significant role in helping doctors make better decisions and even do some tasks independently. But for this technology to work well in everyday medical care, we need to overcome technical problems and make sure that regular people and patients feel comfortable and trust it. Researchers Beam and Kohane [3, 6] noticed this rise in using AI in healthcare. They saw the potential for AI to change how doctors work and improve healthcare. However, in 2020, another group of researchers led by Gao pointed out that for AI in healthcare to be successful, it's about more than just solving technical challenges. People need to be willing to accept and trust this new technology [18]. Doctors can benefit from AI by getting extra help in making more accurate diagnoses and treatment plans. AI can quickly analyze information and find patterns that humans might miss. But for this to happen smoothly, we need the right technology and the support and trust of the general public. It's essential for people to feel confident and okay with AI being used in healthcare. Patients and the public should know that their privacy is protected, that ethical rules are followed, and that AI technology respects the normal relationship between doctors and patients. To make this work, we need to ensure everyone understands AI's benefits in healthcare, addresses worries about data safety, and talks openly about how this technology will be used. By working together to solve both the technical and trust challenges, we can make the most out of AI in making healthcare better for everyone.

In this research, which, as far as we know, is the first attempt to gauge the opinions of participants regarding the privacy and sharing of healthcare data for AI research in KSA, several significant findings emerged. Our study observed that only 52.2% (n = 235) were aware about the AI technology. Our findings were in line with earlier studies [10, 11], in which it was observed that participants generally have limited awareness about AI and its related technologies. This key finding holds significant importance as it underscores the necessity of providing patients with comprehensive education on both the advantages and potential drawbacks of AI in healthcare, particularly if we aim to expand its utilization [19]. We also observed in our findings that 44.7% (n = 201) showed their trust in AI as related to privacy of data. The portrayal of AI in the media [20] often differs significantly from the actual reality. Therefore, it is crucial to foster engagement and education through reliable sources or by introducing practical AI-based health scenarios [10, 11]. This knowledge gap can pose challenges when contemplating the informed consent process for future AI interventions Schiff and Borenstein [9]. Nevertheless, our research revealed that, on the whole, 44.7% of the participants tend to place greater trust in AI and believe that it will take care their privacy concerns. Our study revealed that participants declared it is more bene- fits than risky (n = 250, 55.6%), if the AI analyze the medical records of the patients and 54.2% (n = 244) declared that AI can violate the privacy as far as the patient's records is concerned. One plausible explanation for this observation could be linked to privacy concerns, as elucidated by Aitken [3], and the fear that transferred data may be leveraged for financial gain. This apprehension may be particularly relevant in the context of news organizations, technology companies, and insurance companies.

The analysis of the bivariate logistic regression revealed that younger individuals tend to be more trusting of AI when it comes to safeguarding their data [OR = 0.540, p = 0.040, 95% CI: 0.300-0.972] and gender showed a statistically significant association with the privacy trust on AI [p-value = 0.014**, OR= 0.585, 95% CI; 0.381-0.898]. Although study indicated no significant association between educational level and trust in AI privacy [p-value = 0.615, OR = 1.32, 95% CI; 0.440-4.003], but the OR of 1.32 implies that individuals with higher education levels were 1-fold more likely to trust AI with their data privacy compared to those with lower education highlighting the influence of education in shaping trust in AI. These findings were found consistent with [10, 11] in which it was noted that populations were generally less supportive of data sharing due to privacy concerns with lower educational level. The variance in privacy concerns among age groups may arise from younger individuals possessing a greater understanding of AI compared to their older counterparts. Consequently, it is worthwhile to investigate more profound strategies, including social media, for effectively engaging younger demographics [21, 22].

The results of our study outlined the relationship between people's attitudes towards AI and their willingness to trust it with their data. We found that a significant majority of the individuals surveyed, who had some knowledge of AI, displayed an acceptable level of trust in AI systems when it came to matters of privacy and data sharing for various research purposes. This trust appeared to be closely linked to their openness towards sharing their own data for AI research. In fact, those who had a positive disposition towards contributing their data for AI research were nearly twice as likely to trust AI when it came to safeguarding their data privacy. This underscores the insightful impact of one's willingness to share data on their trust in AI. Moreover, this study also revealed relationship between individuals who advocated for more stringent privacy regulations and their level of trust in AI. Those who expressed a preference for stricter privacy regulations tended to be less trusting of AI when it came to handling their personal data. This highlights the significant role that perceptions of regulatory measures play in shaping people's trust in AI systems. The incorporation of AI into healthcare requires compliance with the specific regulations of individual countries and regions. Factors influencing this finding may encompass considerations related to privacy and data protection laws, such as the European Union's General Data Protection Regulation (GDPR), which imposes rigorous guidelines for the handling of personal and medical data. It is the shared responsibility of healthcare institutions and AI developers to ensure that their systems comply with the relevant rules and regulations. This involves securing informed consent from patients for the utilization of their data and implementing robust security and privacy measures to safeguard sensitive information [21]. Collaboration among AI developers, healthcare professionals, healthcare institutions, and regulatory bodies is imperative to establish robust ethical and legal frameworks that safeguard patient privacy and promote the mutual benefits of AI and medicine. This collaborative, conscientious approach is essential for AI to continue serving as a valuable tool for enhancing medical care and the overall health and well-being of humanity [22, 23]. The authors believe that it holds paramount significance for patients not merely to be apprised of the utilization and privacy of health data in AI research, but to be actively engaged and consulted in every facet of the undertaking [24]. Active participation and counsel from patients and the general populace will guarantee that the application of AI in healthcare remains open, dependable, morally sound, and socially advantageous and trust able.

V. CONCLUSION

In conclusion, the integration of artificial intelligence (AI) into healthcare holds immense potential for revolutionizing medical practices and improving patient outcomes. The discussed research sheds light on the evolving landscape of AI in the Kingdom of Saudi Arabia (KSA) and underscores the need for comprehensive education and awareness campaigns to bridge the gap in public understanding. While a significant portion of the surveyed population expressed trust in AI, concerns regarding data privacy and the ethical use of technology highlight the importance of addressing societal apprehensions. The study's findings emphasize the pivotal role of education in shaping perceptions, as demonstrated by the correlation between age, gender, education, and trust in AI. Younger individuals, possessing a better understanding of AI, and those with higher educational levels demonstrated greater trust. It is imperative to recognize the influence of media portrayal in shaping public opinion and focus on reliable sources and practical AI-based health scenarios for fostering engagement. Moreover, the research reveals the intricate relationship between individuals' attitudes towards AI and their willingness to trust it with their data. Trust is significantly influenced by openness to sharing data for AI research and perceptions of privacy regulations. The study advocates for a collaborative and conscientious approach involving AI developers, healthcare professionals, institutions, and regulatory bodies to establish robust ethical and legal frameworks. Ensuring compliance with data protection laws and actively engaging patients in decision-making processes are identified as essential components for the responsible and trustworthy deployment of AI in healthcare. As the healthcare landscape continues to evolve with technological advancements, the authors emphasize the need for ongoing dialogue, transparency, and patient involvement to maintain AI's openness, dependability, ethical integrity, and societal benefit. The research contributes valuable insights toward fostering a balanced and informed approach to integrating AI into healthcare, ultimately contributing to the enhancement of medical care and the overall well-being of the population.

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