




Perceptions Towards Medical Research Participation: A Study from Jordan

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Purpose: Progress and development in medical researches require the participation of volunteers in such research, but unfortunately, the participation rate is low. This study aimed to assess Jordanian public perceptions towards participation in medical research and to understand motivators and barriers that may affect their participation.

Patients and Methods: This is a cross-sectional study that was conducted from December 2019 to February 2020. Adults from the public were invited to participate in this paper-based survey. The survey assessed public perception (values, trust and ethics), motivators, and barriers towards participation in medical research.

Results: During the study period, 2000 subjects were recruited. Around 82.3% (n = 1643) strongly agreed/agreed that medical research is important for the advancement of science. Helping the society was found to be the main motivators to participate in medical research (n = 1708, 85.4%), while time constrains (n = 1400, 70.0%), lack of opportunity (n = 1278, 63.9%), and the lack of knowledge and awareness about these researches (n = 1152, 57.6%) were among the top barriers towards the participation in medical research. Finally, results showed that previous participation in medical research was correlated with lower overall perception of values and ethics of research, and higher trust in research (p-value <0.001).

Conclusion: Jordanians have positive perception toward participation in medical research, which could be improved by increasing awareness, trust, and training of researchers on responsible conduct of research (RCR) in the country.

Keywords: medical research, perception, value, trust, ethics, Jordan

Introduction

The rapid population expansion that is taking place in the world is automatically linked to a higher prevalence of many acute and chronic diseases within the population.¹ To deal with such health challenges, research institutions are in an urgent need to conduct and carry out medical research studies. Progress and development in medical researches require the participation of volunteers in such research, but unfortunately, the participation rate is low.^{2,3} This may affect the reliability and validity of data obtained and may increase the possibility of occurrence of type II error, where the researchers fail to reject (accept) a false null hypothesis, which may lead to “false negative” conclusion.⁴

Understanding the low rate of participation requires researchers to understand factors that may encourage or discourage potential subjects from participation in medical research. Some studies have been conducted to evaluate such factors in countries such as Saudi Arabia,⁵ Qatar,⁶ Denmark,⁷ Canada,⁸ Australia,⁹ and India.⁹ However, these findings may not be relevant to other populations with different social context.

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In Jordan, there was no previous study that has evaluated the perceptions of Jordanian individuals towards participation in medical research. Therefore, the current study was conducted to assess the Jordanian public perceptions towards participation in medical research and to understand the motivators and barriers that may affect their participation.

Methods

Study Design, Settings, and Subjects

During the period from December 2019 to February 2020, a cross-sectional study was conducted among public in different Jordanian cities. During the study period, adults public (aged 18 years or above) were approached using convenience sampling technique and were invited to participate in this paper-based self-administered survey. Publics were approached at different places including public areas, such as malls, parks, and at their homes as well. Before completing the survey, participants were provided with detailed description the study purpose, and were ensured that their participation is voluntary, and their responses would be kept anonymous. Additionally, they were asked to sign a written informed consent form. The protocol of this study was approved by the Institutional Review Board of Jordan University of Science and Technology (Approval number 23/128/2019).

Survey Development

A comprehensive literature review of multiple databases (Medline/PubMed, and Google Scholar) was performed to identify relevant literature regarding public perception towards participation in medical research. Based on the results of the reviewed literature, a questionnaire was built to assess the Jordanian public perceptions towards participation in medical research and to understand the motivators and barriers that may affect their participation.^{5,10} The initial draft of the survey was content, and face validated to a group of experts to provide their feedback and the survey was modified accordingly. Then, the final draft of the questionnaire was pilot tested to a group of 30 public to provide their advice regarding the clarity and comprehensibility of the questions, and the response from those subjects were excluded from the final analysis.

The final version of the questionnaire included three sections: 1) Part I which assessed demographic characteristics of the study sample; 2) Part 2 that evaluated perception towards participation in medical research. In this

section statements were divided into three areas of interest: statements related to values that medical research brings, statements related trust in medical research, and statements related to ethics in medical research. To assess perception a five-point Likert scale (strongly agree, agree, neutral, disagree, and strongly disagree) was used. The third part of the questionnaire assessed the public's perception towards motivators, and barriers to participation in medical research.

Regarding the second part of the questionnaire, a perception score was calculated for each of the three areas (value, trust and ethics). For those statements that support medical research the coding of the 5-point Likert scale was strongly agree (5), agree (4), neutral (3), disagree (2), and strongly disagree (1), while for those statements against medical research, the coding system was strongly agree (1), agree (2), neutral (3), disagree (4), and strongly disagree (5). Then, a mean score for each area was calculated for each participant. Thereafter, each score was converted to percent of maximum possible (POMP) to end up with scores ranging from 0–100%

Statistical Analysis

Data were analyzed using statistical package for social science (SPSS[®]) version 22 (SPSS[®] Inc., Chicago, IL, USA). A descriptive analysis was done using mean and SD (or median (Interquartile range [IQR]) for continuous variables and percentages for categorical variables. Checking for data normality was carried out using the Shapiro–Wilk test (with P-value ≥ 0.05 indicating a normally distributed continuous variable). Differences in perceptions scores between those who participated in medical research and those who did not were evaluated using Mann Whitney *U*-test. For all statistical analyses, all tests were two-tailed and a P-value < 0.05 was considered statistically significant.

Results

Socio-Demographic Characteristics of the Study Sample

During the study period, 2,143 subjects were approached to fill the study survey, where 2,000 subjects agreed to do so. Thus, the response rate in this study was 93.3%. The mean age participants was 29.1 years (SD = 10.3). Two-third of them were females ($n = 1339$, 67.4%), and around half of them held a bachelor's degree or higher ($n = 948$, 47.7%), and almost half of them were married ($n = 913$,

45.8%). Most of the participating subjects (n = 1762, 88.9%) were from the low-income category (<500 JD/month), and almost all of them were Muslims (n = 1967, 98.4%). Among the recruited subjects 18.1% (n = 361) reported that they have ever participated in a medical research. Table 1 describes the socio-demographic characteristics of the study participants.

Participants Perception Towards Participation in Medical Research

When participants were asked about the values medical research bring to them once they participate in such research (Table 2), around 82.3% (n = 1643) strongly agreed/agreed that medical research is important for the advancement of science and 79.7% (n = 1594) believed that medical research is important because it results in new and improved treatments for diseases. Expectedly, low proportion of the participants (n = 499, 25.0%) believed that medical research may harm society.

Regarding trust in medical research (Table 2), around 67.5% (n = 1350), and 65.5% (n = 1310) strongly agreed/agreed that medical research information provided by pharmaceutical companies and those provided by academic institution can be trusted, respectively. While only 41.1% (n = 822) thought that media accurately describes medical research.

Considering ethics in medical research (Table 2), only 26.1% (n = 521) of participants agreed that doctors force their patients to participate in medical research, and 31.8% (n = 636) of them believed that human participants in certain medical research are treated like experimental animals. In the same fashion, 33.3% (n = 665) of participants think that if patients decide not to participate in research their doctors will not give them good care.

Motivator and Barriers to Participate in Medical Research

When study participants were asked to determine the personal and societal motivators that encourage them to participate in medical research (Figure 1). Societal benefits were found to overwhelm individual benefits as motivators to participate in medical research. Of the study participants, 85.4% (n = 1708) indicated that they may participate in medical research since it may help the society, and 83.1% (n = 1662) agreed that helping in advancing the medical knowledge is among the main motivators for their participation. On the other hand, for personal benefits as

Table 1 Demographic Characteristics of the Study Sample at Baseline (N = 2000)

Parameters	Mean (SD)	n (%)
Age (years)	29.1 (10.3)	
Gender		
• Female		1,339 (67.4)
• Male		648 (32.6)
Educational level		
• Low (school level or lower)		1,040 (52.3)
• High (University of higher)		948 (47.7)
Employment		
• Working full time		560 (28.6)
• Working part time		115 (5.8)
• Retired		51 (2.6)
• Self-employed		97 (4.9)
• Homemaking/caregiving		304 (15.3)
• Studying		642 (32.3)
• Looking for work		211 (10.6)
Personal income		
• <500 JD/month		1,762 (88.9)
• >500 JD/month		219 (11.1)
Marital status, n (%)		
• Married		913 (45.8)
• None-married (single, divorced, widowed)		1,079 (54.2)
Religion		
• Muslim		1,967 (98.4)
• Christian		20 (1.0)
• Other		11 (0.6)
Place of residence		
• Amman		171 (8.6)
• Other		1820 (91.4)
Have you ever participated in a medical research?		
• Yes		361 (18.1)
• No		1,631 (81.9)

Note: 1 US\$ = 0.71 JD.

motivators, only 30.3% (n = 606) felt that they would participate in medical research to achieve healthcare benefits to their friend and relatives; and 40.4% (n = 808) may participate to get financial compensation.

Nine statements were used to assess barriers towards the participation in medical research (Figure 2). Among those barriers, the three top ones were: time constrains (n = 1400, 70.0%), lack of opportunity (n = 1278, 63.9%), and the lack of knowledge and awareness about the researches (n = 1152, 57.6%). While the least reported

Table 2 Public Perception Towards Participation in Medical Research Studies (N = 2000)

Statements	Strongly Agree/ Agree
	n (%), [95% CI]
Values that Medical Research brings	
Medical research is an essential step in developing new drugs ^a	1,614 (80.7), [79.0–82.4%]
Medical research harms society ^b	499 (25.0), [23.1–26.9%]
Medical research is important for the advancement of science ^a	1,643 (82.3), [80.6–84.0%]
Hospitals that participate in medical research provide better healthcare ^a	1,549 (77.5), [75.7–79.3%]
The most important reason for conducting medical research is financial gain ^b	640 (32.0), [30.0–34.0%]
Medical research is important because it results in new and improved treatments for diseases ^a	1,594 (79.7), [77.9–81.5%]
Trust in Medical Research	
The government always adequately protects the public against unethical medical research ^a	1,310 (65.5), [63.4–67.6%]
Medical research information provided by pharmaceutical companies can be trusted ^a	1,350 (67.5), [65.4–69.6%]
Medical research information provided by academic institutions can be trusted ^a	917 (45.9), [43.7–48.1%]
The media accurately describes medical research ^a	822 (41.1), [38.9–43.3%]
Ethics in Medical Research	
Doctors force their patients to participate in medical research ^b	521 (26.1), [24.2–28.0%]
Human participants in certain medical research are treated like experimental animals ^b	636 (31.8), [29.8–33.8%]
Participation in medical research is entirely voluntary ^a	1,218 (60.9), [58.8–63.0%]
Participants in medical research get adequate compensation for their participation ^a	1,048 (52.4), [50.2–54.6%]
Confidentiality of research participants is adequately protected ^a	1,392 (68.1), [66.1–70.1%]
All the results of medical research are made available to the public ^a	1,109 (55.5), [53.3–57.7%]
Participants in medical research get adequate information about the research they participate in ^a	1,275 (63.8), [61.7–65.9%]
If you decide not to participate in research your doctor will not give you good care ^b	665 (33.3), [31.2–35.4%]

Notes: ^aPositive statements with the coding system: 5: strongly agree, 4: agree: 3: neutral, 2: disagree, 1: strongly disagree. ^bPositive statements with the coding system: 5: strongly disagree, 4: disagree: 3: neutral, 2: agree, 1: strongly agree.

barriers were moral reasons (n = 690, 34.5%), lack of interest (n = 690, 34.5%) and lack of trust in the research conductors (n = 726, 36.3%).

Relationship Between Participants’ Perception in Medical Research and Their Previous Participation in Medical Research

When comparing the overall perception score for the three area of interests (values, trust and ethics) for those who have ever participated in medical research and those who did not (Table 3), respondents who did not have a previous participation in medical research showed better perception towards the value that medical research brings, and towards the ethical respect in medical research, while they showed lower trust value in those researches (P-value <0.001).

Discussion

This survey-based study aimed to identify public perception towards the participation in medical research in Jordan. It

demonstrated that participants showed positive perception toward participation in medical research, with societal benefits identified to be the most important motivator for their participation. On the other hand, time constrains, lack of opportunity, and deficient knowledge and awareness about these researches were considered the main barriers of participation in research. Moreover, results showed that previous participation in medical research was correlated with lower overall perception of values and ethics of research, yet, a higher trust in research.

Medical research is essential for the development of healthcare in the society. For example, medical research provides important insights about etiology and risk factors of diseases, management of diseases, and efficiency of health care system.¹¹ In the current study, 18.1% of participants reported that they have ever participated in a medical research. In addition, the majority (80–82%) believed that medical research is important for the advancement of science and advances treatments of diseases. Variations in the willingness to participate in medical research was reported in the world populations. For example, in a study that was conducted in Canada, 30%

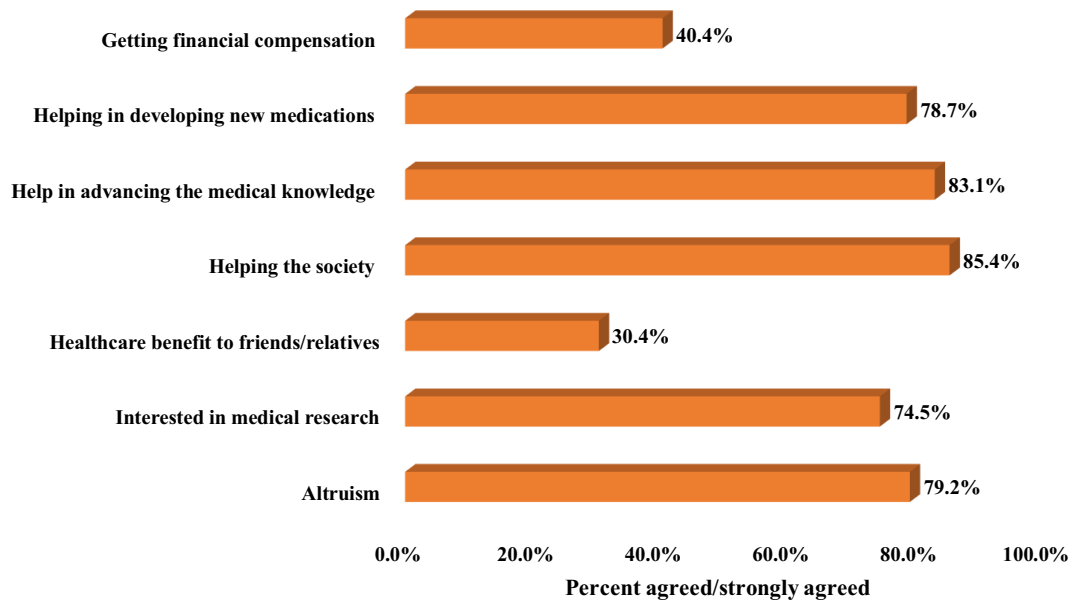


Figure 1 Motivators to participate in medical research (n = 2000).

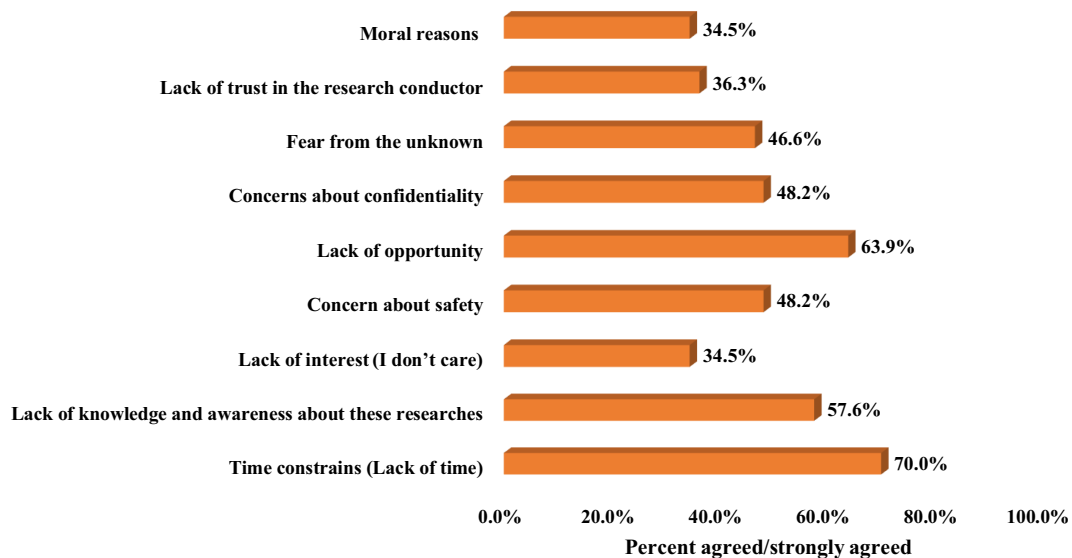


Figure 2 Reasons for declining consent to participate in research (n = 2000).

reported that they have ever participated in research and 68% had positive attitude toward participation in clinical trials.¹² A study from Qatar showed that about 63% of the surveyed participants were positive toward participation in medical research.⁶ High willingness (86%) to participate in biobank medical research was reported in an Italian study,¹³ whereas low willingness (about 50%) was reported in a study from USA.¹⁴

The present study showed that societal benefits and advancing the medical knowledge were the main

motivators for participation in research. In addition, factors such as healthcare and financial benefits were also among motivators that encourage participation in medical research. In a qualitative study that examined attitude of Arabs in the USA toward health research participation, benefits; clinicians as recruiters and social relationships, and the cost of research participation were among factors that impacted participation.¹⁵ In a study from Qatar, factors such as helping others and getting access to health care were the prime motivators for participation in clinical

Table 3 The Relationship Between Respondents' Perception Towards Medical Research and Their Previous Participation in Medical Research (N = 2000)

Perception Area	Participation in Medical Research Median (IQR)		P-value#
	Yes	No	
Values score	66.7 (16.8)	70.8 (16.7)	<0.001*
Trust score	68.8 (25.0)	62.5 (25.0)	<0.001*
Ethics score	59.4 (15.6)	62.5 (15.6)	<0.001*

Notes: #Using Mann-Whitney U-test, *significant at 0.05 significance level.

Abbreviation: IQR, interquartile range.

research.⁶ Social responsibility was a key factor for participation in medical research in Cambodia.¹⁶ Having a relative or friend who has an illness has been shown to positively impact willingness to participate in medical research in the USA.¹⁴ In the UAE, results from the Abu Dhabi cohort study showed that altruism and personal relevance were commonly identified motivators of participation in medical research.¹⁷ Thus, motivators of medical research participation were similar among many world populations.

The current study reported that time constrains, lack of opportunity, the lack of knowledge and awareness about medical research, moral reasons, lack of interest and trust as barriers that face participation in medical research in Jordan. In the Gulf countries such as Kuwait, Qatar and UAE, factors such as time constrains, lack of awareness about clinical research and lack of interest were reported to be major barriers of participation in medical research.^{6,17,18} Thus, similar barriers of participation in medical research were reported in different studies from the region. Interventions at the region's level are, therefore, may be needed to overcome such barriers.

Among ethical issues raised by the current investigation were trust in medical research and that doctors might influence the decision of their patients to participate in medical research. Several ethical challenges were reported to face the conduction of medical research in the Arab world. These include IRB approvals, informed consent process, privacy, confidentiality, and adequate ethics training.¹⁹⁻²⁵ Adoption of research ethics guidelines and implementation of training on responsible conduct of research (RCR) in the academic and research institution in the region might overcome most of such challenges.^{21,26,27}

Notably, the current study has shown that previous participation in medical research was correlated with lower overall perception of values and ethics of research, yet, higher

trust in research. Such results indicate the need form researchers to improve research experience among medical research participants to leave a more positive perception among them. This could also indicate the need to train researcher on best practices human research, research ethics, and protection for medical research subjects.²⁵

This study comes with some limitations, as the survey did not explore the effect of financial incentive that participants' may receive as a remuneration for their participation in medical research on their perception towards the participation in medical research. Future work should explore this in more detail. Furthermore, participants in this survey may tend to show positive perception to exhibit blessing behavior. Additionally, perception to participate in medical research may be affected by several factors that were not measured or covered in this study. This study participants could have been influenced by an unintentional selection bias as the fraction of participants who have previously been involved in medical research was 18.1%, which is higher than what was expected. Finally, as is the case in most questionnaires, measuring patient views of participation in medical research, psychometrics, namely, principal component analysis and reliability, were not done in this study.²⁸ In the future more comprehensive studies are needed to cover these limitations.

In conclusion, Jordanians have positive perception toward participation in medical research. This perception can be further improved by increasing awareness, trust, and training of researchers on RCR in the country.

Author Contributions

All authors made substantial contributions to conception and design, acquisition of data, or analysis and interpretation of data; took part in drafting the article or revising it critically for important intellectual content; agreed to submit to the current journal; gave final approval of the version to be published; and agree to be accountable for all aspects of the work.

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Disclosure

The authors report nopotential conflicts of interest for this work.

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