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Perceptions and attitudes to clinical research participation in Qatar

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ABSTRACT

Recruitment into clinical research studies is a major challenge. This study was carried out to explore the perceptions and attitudes towards clinical research participation among the general public in Qatar. A population based questionnaire study was carried out at public events held in Qatar. Residents of Qatar, 18 years or above in age were surveyed, anonymously, following verbal consent. Descriptive and multivariate analyses were conducted. We administered 2517 questionnaires to examine clinical research participation, of which 2379 complete forms were analyzed. Those who had previously been approached to participate in research completed a more detailed assessment. Data showed that only 5.7% participants (n = 134) had previously been approached to participate in a clinical research study. Of these 63.4% (n = 85) had agreed to participate while 36.6% (n = 49) had declined. The main reasons for declining participation included: time constraint (47.8%, n = 11), 'fear' (13.0%, n = 3), lack of awareness about clinical research (8.7%, n = 2) and lack of interest (8.7%, n = 2). 'To help others' (31.8%, n = 27) and 'thought it might improve my access to health care' (24.7%, n = 21) were the prime motivators for participation. There was a general agreement among participants that their previous research experience was associated with positive outcomes for self and others, that the research conduct was ethical, and that opportunities for participation will be welcomed in future. More than ten years of stay within Qatar was a statistically significant determinant of willingness to participate, adjusted odds ratio 5.82 (95% CI 1.93–17.55), p = 0.002. Clinical research participation in Qatar needs improvement. Time constraints, lack of trust in and poor awareness about clinical research are main barriers to participation. Altruism, and improved health access are reported as prime motivators. Deeper insight in to the factors affecting clinical research participation is needed to devise evidence based policies for improvement in recruitment strategies.

1. Introduction

Recruitment into clinical research studies is a major continuing challenge [1]. The general public and patients are still not fully aware of the importance of participation in clinical research studies for the development and implementation of medical advances [2]. Not all clinical research studies meet their recruitment targets, and as few as 6% of eligible subjects may participate in a clinical research trial [3,4].

Insufficient recruitment into research studies has significant implications [3]. Clinically important findings may be missed due to statistical non-significance, preventing or causing delays in demonstrating the value of interventions in clinical practice [2]. Many clinical research trials are abandoned or produce equivocal results due to recruitment difficulties. This leads to loss of return on the resources expended in designing, developing, setting up, and conducting a clinical research trial as well as implications for the reputation of study investigators and institutions associated with an unsuccessful study [2,4].

The Middle East and North Africa (MENA) region is undergoing rapid development and population expansion. This has been accompanied by an increasing prevalence of both acute and chronic medical disorders. In particular, there is an alarming increase in the prevalence of obesity and type 2 diabetes mellitus, particularly in countries that are part of the Gulf Cooperation Council (GCC). To tackle the region's health challenges, there is an urgent need for clinical research studies, and in particular, randomized controlled trials. Clinical trial participant density in the MENA region is less than 1%, suggesting that a sizable population has not yet been engaged in clinical research [5]. Clinical research remains under-developed in the MENA region. Despite growing investment supported by the wealth of the region, clinical research in the MENA region accounts for 0.5% of the total global clinical trial sites compared to 66% in North America and Western

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Europe [6].

While there are structural and demographic challenges for the successful conduct of clinical research in the MENA region, little is known about perceptions of clinical research by potential participants. Surveys of attitudes to research participation in the MENA region have been limited [7]. To improve the success of clinical research studies, it is necessary to identify and explore the factors involved in low study enrollment and the public's perceptions towards research [2]. The aim of our study was to determine the perceptions towards clinical research in Qatar, a GCC country, where there is an increasing need to determine effective approaches to key medical disorders through the conduct of successful clinical research studies.

2. Methods

A questionnaire survey was conducted at two major public events held in Doha in Qatar between December 2014 and February 2015. National events are well attended in Qatar. The events for data collection marked Qatar's National Day and Qatar's National Sports Day, respectively. Both events attract large numbers of people from all backgrounds, therefore closely representing Qatar's multicultural population. Of the 2.3 million population in Qatar, the indigenous Qataris make up between 10 and 15% [8] [9], while the rest are expatriates. The proportion of Qataris in our study was 10.5% while remainder were expatriates.

The survey was conducted to explore the existing attitudes and behaviors prevalent among the population in Qatar. All visitors who came to a health awareness booth and who were able to speak, read and understand Arabic or English were approached about completing an anonymous survey and consented verbally by majority female clinical research coordinators. A semi structured questionnaire, available in English and Arabic, was then completed with residents of Qatar who were 18 years or above in age. Those who had previously participated in research studies were asked to rate a set of 23 pre-defined statements relating to their research experience on a Likert Scale ranging between Strongly Disagree to Strongly Agree. Tourists and visitors were excluded. The anonymous survey was approved and given exempt status by the Joint Institutional Review Board (JIRB) of Weill Cornell Medicine - Qatar and Hamad Medical Corporation (Doha, Qatar).

2.1. Statistical analysis

Completed surveys were analyzed on SPSS version 23. Descriptive analyses were conducted along with univariate and multivariate analyses to explore the relationships amongst different variables and willingness to participate in clinical research. Univariate analysis was performed by using Pearson's Chi Square tests and multivariate analysis using logistic regression. All potential confounding variables (gender, age, BMI, length of stay, education level, employment and comorbidity) were included in the final multivariate logistic regression model. Multicollinearity was assessed by performing bivariate linear regression between the variables and calculating the variance inflation factor (VIF). A VIF of < 2.5 was deemed to indicate no evidence of multicollinearity [10]. A two sided P value of < 0.05 was considered to be statistically significant. Participants were divided into three categories based upon their country or region of origin: Qataris (Q), Non-Qatari Arabs (NQA) and Non-Arabs (NA).

3. Results

A total of 2517 adults were surveyed with 2379 valid responses. Invalid surveys included those from ineligible participants (visitors or less than 18 years old individuals) or insufficient data (missing all or 90% or more of the responses to the survey). Approached subjects were approximately equally distributed by gender (females, 46%), and were employed (70%), living in Qatar ≤10 years, and had a good level of education (72% with college education and above) (Table 1). The majority of the surveyed population had never been approached or invited to participate in a clinical research study. These did not vary by length of stay (88.5% length of stay ≤10 years, 89.1% length of stay > 10 years). Of the 5.6% participants (n = 134) who had previously been approached to participate in clinical research, 63.4% (n = 85) had agreed to participate while 36.6% (n = 49) had declined. Data for this question was missing for the remaining 5.6% (n = 132) surveyed.

Table 1
Demographic characteristics of surveyed population with valid responses (n = 2379).

Gender, n (%)	Males	1267 (54.0)
	Females	1081 (46.0)
Age, n (%)	18-24 years	208 (8.9)
	25-34 years	934 (39.7)
	35-44 years	895 (38.1)
	45-60 years	281 (12.0)
	> 60 years	33 (1.4)
Level of Education, n (%)	Below Elementary or None	52 (2.2)
	Elementary	61 (2.6)
	Secondary	539 (23.2)
	College and above	1669 (71.9)
Employment, n (%)	Currently Employed	1643 (70.0)
	Not employed	709 (30.0)
Working[a] Hours/week, n (%)	≤40 h	899 (58.2)
	> 40 h	645 (41.8)
Length of Stay, n (%)	≤10 years	1438 (68.7)
	> 10 years	655 (31.3)
Comorbidity[+], n (%)	Yes	336 (14.4)
	No	2004 (85.6)
Nationality, n (%)	Qatari	201 (9.9)
	Non Arab	869 (42.6)
	Non Qatari Arab	969 (47.5)

[a] Employed subjects only; +Comorbidity e.g. diabetes, hypertension.

3.1. Participants in clinical research

Among those who had previously participated in a clinical research study, 48.8% were Non-Arab nationalities (n = 41), 41.7% were Non-Qatari Arabs (n = 35) and 9.5% were Qatari participants (n = 8).

There were no significant differences observed in the demographic characteristics of the three groups. However, while the majority of Qatari participants were between 25 and 34 years of age, the Non-Qatari Arabs and Non-Arab participants were mostly in the age group between 35 and 44 years, with the majority having resided in Qatar for ten years or less. The majority of participants in all three groups were well-educated with four years of college or above education and employed at the time of the survey.

In those who had participated in research, male participants (60.2%, n = 50) outnumbered female participants (39.8% n = 33). The majority of participants were between 25 and 44 years of age (69.4%, n = 59) with a little over half having resided in Qatar for less than or equal to ten years. Participants in this group displayed high levels of education with approximately two thirds having attained a college degree or above. A similar proportion were employed at the time of survey. No participant in this cohort had received less than elementary education (Table 2).

Those who had lived in Qatar for over ten years were more likely to have participated in research than those who had lived for ten years or under. This was statistically significant in both the univariate (p = 0.004) and multivariate (p = 0.002) analyses (Table 3). Those who resided in Qatar for more than ten years were almost 6 times more likely to have participated in a clinical study, adjusted odds ratio 5.82 (95% CI 1.93–17.55).

Participants had mostly participated in studies about diabetes (37%) and heart disease (7.4%), which are common health problems in Qatar. Simple data collection methods such as questionnaires (n = 39),