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Are first generation immigrants more inclined to participate in clinical research?

Aisha Farha

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Are First-Generation Immigrants More Inclined to Participate in
Clinical Research?

by

Aisha Farha

Thesis

Submitted to the School of Health Sciences

Eastern Michigan University

in partial fulfillment of the requirements for the degree of

MASTER OF SCIENCE

in

Clinical Research Administration

Thesis Committee:

Irwin Martin, Ph.D., Chair

Jean Rowan, MD M.S.

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Ypsilanti, Michigan

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Abstract

The number of immigrants entering the United States has increased dramatically in the past 30 years, but minorities and ethnic groups are underrepresented in research studies. This study examined first- and second-generation Arab American immigrants in Dearborn, Michigan, using a survey from 65 participants to determine the impact of generation on clinical research participation. Fifty-one (78%) of the respondents were first-generation immigrants, and 14 (22%) were second generation. There was no statistical difference between first- and second-generation immigrants in their willingness to participate in clinical research. Further research with a larger and more diverse population is needed to evaluate willingness to participate in clinical trials by generation in Arab Americans.

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Chapter 1: Introduction

There is a growing population of immigrants in the United States, estimated to be 13.3% as of 2014 (Camarota & Zeigler, 2016). In 2017, there were over 43 million residents who were immigrants in the United States, which makes up 13.4% of the total population (López & Bialik, 2017).

Among these immigrants, the Arab American population is the fastest-growing population in the United States (Haddad, Al-Bashaireh, Ferrell, & Ghadban, 2017). According to the US Census (2010), Arab Americans constitute more than 3.7 million people in the United States. An Arab born in a foreign country but living in the United States is considered an immigrant. An immigrant can be a first- or second-generation immigrant. First generation is defined as “an immigrant, a foreign-born resident who has relocated and become a citizen or permanent resident, in a new country” (Moffett, 2017, p.4). Second generation is defined as “an individual who was naturally born in the relocated country to one or more parents who were born elsewhere and are not U.S. citizens living abroad” (Moffett, 2017, p.4). Many of these Arab American immigrants have relocated to the United States in order to improve their living conditions. Among those improvements is access to healthcare tailored to meet their needs. Since different genetic groups are affected by certain diseases more than other groups, it is important to provide treatment options to Arab Americans based on their genetic makeups. Unfortunately, research focusing on or recognizing Arab Americans as a group is lacking.

There are barriers that exist in clinical research for both the participant and the researcher, especially in ethnic minorities. Barriers to participation can include: misunderstanding of cultural knowledge, beliefs of others from a different cultural background, lack of trust in the healthcare system, difficulty understanding the language, or lack of awareness of limited available resources, such as transportation or child care. In fact, one of the major barriers in clinical research is the lack of knowledge about the cultural differences among immigrants. In order to improve participation rates, one should understand cultural and language differences (George, Duran & Norris, 2014) that impact an individual's willingness to participate in clinical trials. Furthermore, despite these barriers, participation in clinical research needs to be culturally diverse to be able to improve immigrants' participation in clinical trials in order to bridge the gap in health care and research (Hershenberg, Drabick & Vivian, 2012)

Chapter 2: Background

Immigrants in the United States must overcome many challenges (Jaber, 2002). These include barriers such as language, culture, and religion. There is a need to educate immigrants in the United States about the value of participation in clinical research. Failure to do so could result in a loss of valuable findings in epidemiological studies.

In a study conducted by (Han, Kang, & Kim, 2006). 14 studies were analyzed which included 2,400 Korean Americans. Their study focused on multiple challenges faced by Korean Americans such as recruitment barriers. In review of the findings from the study, the authors determined that two factors contribute to participation barriers. These two factors were found at the individual and community level. At the individual level, they found that cultural attitudes, language, gender, and age played a role, and at the community level, reduced healthcare coverage, lack of awareness, lack of education regarding healthcare prevention, the inability/reluctancy of gatekeepers to educate and advise, and the types of research all contributed to the barriers faced by research on immigrants.

The research conducted by Salman, Nguyen, & Lee, (2016); focused on data obtained from research regarding cancer patients. In all, they chose 28 articles to review with eight being written by nurses. In the context of their review, Salman et al. (2016) found that three barriers were related to the lack of immigrant outcome: physician, patient, and system related conflicts. According to the authors, the physicians were hindering the process by several mechanisms which stemmed from their lack of awareness, attitudes towards the trials, bias, lack of communication, and concern regarding the cost to patients. On the patient level, age, gender, ethnicity, socioeconomic status, and perceptions all contributed to the lack of participation.

Finally, the system at large was responsible for the unfortunate outcome because it failed in the areas of design, inclusion/exclusion, and access/cost of health care to participants. According to these authors, overcoming these barriers will help to increase participation in the future.

According to Smith et al. (2018), the major contributing factor raising the barriers to clinical research stems from lack of communication in the immigrant's native language. After conducting research on 19,453 cancer patients over a 10- year period, the authors divided their sample into three groups: English- speaking patients (non-CALD), culturally and linguistically diverse patients whose preferred language was English (CALD-PLE), and culturally and linguistically diverse patients whose preferred language was not English (CALD-PLNE). Among these groups, it was found that language barriers contributed to the lack of participation in clinical trials. Of the 19,453 patients analyzed, 10,675 (54.9%) of the participants were categorized as non-CALD; 3,217 (16.5%) were CALD-PLE; and 3,601 (18.5%) were categorized as CALD-PLNE. Of the non-CALD patients, 8.4% were enrolled in a study, while 91.6% were not. Of the CALD-PLE patients, 7.7% were enrolled while 92.3% were not. Lastly, of the CALD-PLNE patients, 3.9% were enrolled while 96.1% were not. Only 50% of the patients who communicated less easily in English participated in a study. These authors concluded that the results indicated that a growing need for better communication within the field was warranted.

Purpose of the Study

The objectives of this study were to evaluate the willingness of individuals who were first- or second-generation immigrants to participate in clinical trials.

Research Question 1.

Is there a difference in willingness to enroll in clinical research studies between first- and second-generation immigrants?

Research Question 2.

Is there a difference in participation based on age, gender, or education?

Chapter 3: Research Design and Methodology

The study survey was approved by the University Human Subjects Review Committee (UHSRC) at Eastern Michigan University (Appendices A and B). To participate in this study, participants had to agree to the terms of the consent form (Appendices C and D).

This study was designed to evaluate the willingness of individuals who were first- or second-generation immigrants to participate in clinical trials.

After obtaining approval from the UHSRC at Eastern Michigan University for this study survey, and after the participants agreed to the terms of the study via consent forms, a random survey questionnaire was emailed to 250 members of the Al-Salam Islamic Center in Dearborn, Michigan, in May 2018, available in both English and Arabic (Appendices E and F).

The survey consisted of 18 questions in total and included demographic questions such as age, gender, marital status, and education.

The primary endpoint was to discover if there is a difference between second-generation and immigrants in willingness to enroll in clinical research. The secondary endpoint was to determine if there is a difference in potential participation based on any demographic variable.

Data Analysis:

Data collected from the survey were initially entered into Microsoft Excel. Later these data were uploaded to Statistical Package for the Social Sciences (SPSS) v25 format, in which each question and its options were categorized into ordinal and nominal data. The transcribed data were analyzed for demographic variables and other possible parameters to answer the research questions. Responses from first- and second-generation immigrants were grouped for analysis. Data analysis was conducted using the Pearson's chi-square test and Fisher's exact test to evaluate the data and examine differences between groups. It should be noted that the alpha level used for all tests of significance was $\alpha = .05$. Correlations were explored for the generation variable in relation to other variables.

Chapter 4: Results

The survey conducted included an analysis of 65 individuals that agreed to participate from the 250 that were emailed. Fifty of the responses were in the English version and the other 15 in the Arabic version. The response rate was 26%. According to this survey, 56 (86%) of the participants were immigrants, and nine (13.8%) were non-immigrants. Of those immigrants, 51 (78%) were first generation (“Generation 1”), 10 (21.5%) were second (“Generation 2”) participants, and four were third generation (“Generation 3”) participants. Forty (61%) of the respondents were between the ages of 18 and 34, which includes 30 participants from first generation and 10 from second and third generations. Thirty-five (53.8%) of the participants from first generation and 10 (78.6%) from second generation or more had a bachelor’s degree or greater. The majority (41;63%) of first-generation participants were of Middle Eastern nationality. In addition, 63 (97%) of the individuals who participated in the survey were Muslim across all generations. A more detailed result of demographic data is presented in Table 1.

Table 1: *Demographic Characteristics of Survey Participants*

Gender	Females Males	<i>n</i> = 44 (68%) <i>n</i> = 21 (32%)
Age	18-24 25-34 35-64 ≥65	<i>n</i> = 19 (29%) <i>n</i> = 2 (32%) <i>n</i> = 22 (34%) <i>n</i> = 4 (6%)
Level of Education	High School or Less Associate's Degree Bachelor's Degree ≥ Master's Degree	<i>n</i> = 9 (13.8) <i>n</i> = 6 (9%) <i>n</i> = 40 (61.5%) <i>n</i> = 11 (16.9%)
Nationality	US Yemen Iraq Middle Eastern Other	<i>n</i> = 11 (16.9%) <i>n</i> = 6 (9.2 %) <i>n</i> = 0 <i>n</i> = 41 (63%) <i>n</i> = 3 (4.6%)
Religion	Protestant Catholic Muslim Jewish Buddhist Other/no answer	<i>n</i> = 1 (1 %) <i>n</i> = 1 (1%) <i>n</i> = 63 (97%) <i>n</i> = 0 <i>n</i> = 0 <i>n</i> =1 (1.5%)
Marital Status	Married Single Prefer not to answer	<i>n</i> = 29 (44.6%) <i>n</i> = 34 (52%) <i>n</i> = 2 (3%)

Of the 65 individuals who participated in the survey, there were 51 first-generation immigrants, of whom 36 (70.6%) were females. In addition, there were six males and eight females from second and third generations. Thus, overall 68% of the participants were females. A chi-square analysis comparing participant's generation and gender revealed a p-value of 0.056 (see Figure 1). This means that more than 50% of the participants were females from both generations.

A number of notable demographic differences across all generations were seen. First, more Generation 1 participants were included in the study. In addition, more female participants

were included in the study from first generation than second and third generation. Furthermore, the average age for most of first-generation participants was between 18 and 34.

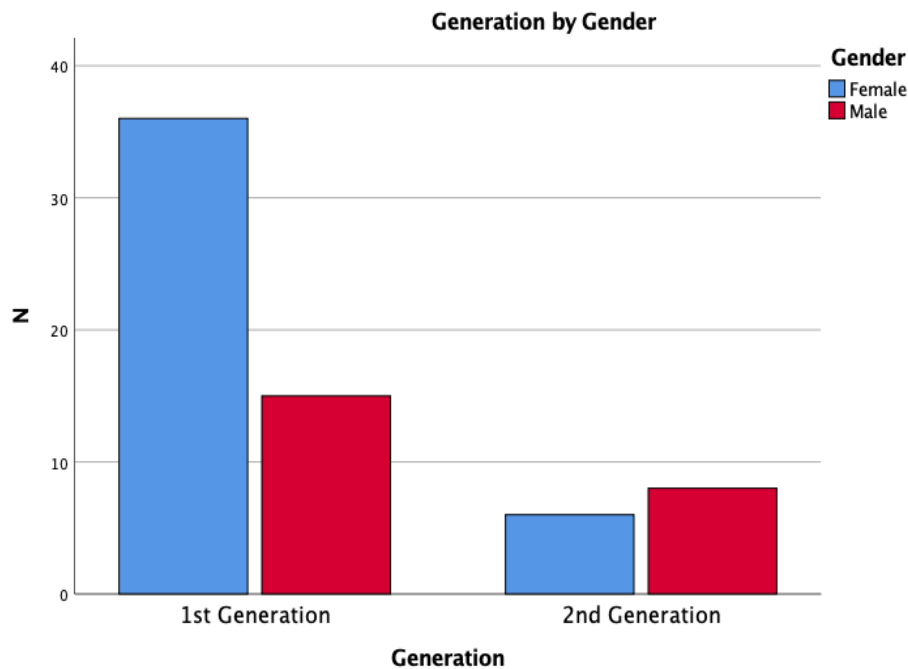


Figure 1. Participants' gender compared by generation.

Of those who participated, 26 (51%) from Generation 1 said they would be willing to participate in future clinical trials, and 25 (49%) declined. Seven (50%) of the second-generation participants said they would be willing to participate in future clinical research, and the other 50% declined. When participants were asked reasons for their willingness to participate in future clinical trials, 23 (35%) of first-generation participants said, "If I get paid," and 17 (26%) said "to help future generations." Furthermore, 16 (24.6%) from second generation said, "I don't want to be used as a guinea pig," and nine (13.8%) selected the most common reason for not willing to participate as "I do not know if it would be safe" (see Table 2).

Table 2 Reasons for Considering Participating or Not Participating in a Clinical Trial

Reasons for Participating	<i>n</i> (%)	Generation	Reasons for not participating	<i>n</i> (%)	Generation
If I get paid	21 (32.3%)	First generation 23 (35%)	I do not want to be used as a guinea pig	10 (15.3%)	Generation 1 16 (24.6%)
To help future generations	28 (43%)	First generation 17 (26%)	I do not know if it would be safe	29 (44.6%)	Generation 2 9 (13.8%)

When the question “How knowledgeable are you about clinical research?” was asked, 40 (78%) respondents from Generation 1 had at least a little knowledge about clinical trials, and eight (15.6%) from Generation 1 had no knowledge of clinical trials. In addition, 10 (71.4%) respondents from Generation 2 who had at least a little knowledge about clinical research and one (7%) respondent who was completely knowledgeable about clinical research (Table 3). A Spearman’s rank-order correlation revealed a weak correlation between the variables generation and knowledge ($p = .056$). In addition, participants across both genders and both generations had little knowledge of clinical trials. Another Spearman’s rank-order correlation showed a positive significance for a relationship between knowledge and outcome ($p = .033$).

Table 3

Knowledge About Clinical Trials by Generation

Knowledge	Generation 1 n (%)	Generation 2 n (%)
Not at all knowledgeable	8 (15.6%)	3 (21%)
A little knowledgeable	20 (39%)	4 (28.5%)
Somewhat knowledgeable	20 (39%)	6 (42.8%)

When the participants in this survey were asked, “What is your highest level of education?” 35 (68.6%) from Generation 1 had a bachelor’s degree or more, and 16 (31.4%) had an associate’s degree or less. There were 11 (78.6%) from Generation 2 with a bachelor’s or more and 4 (21.4%) with an associate’s or less (see Figure 2).

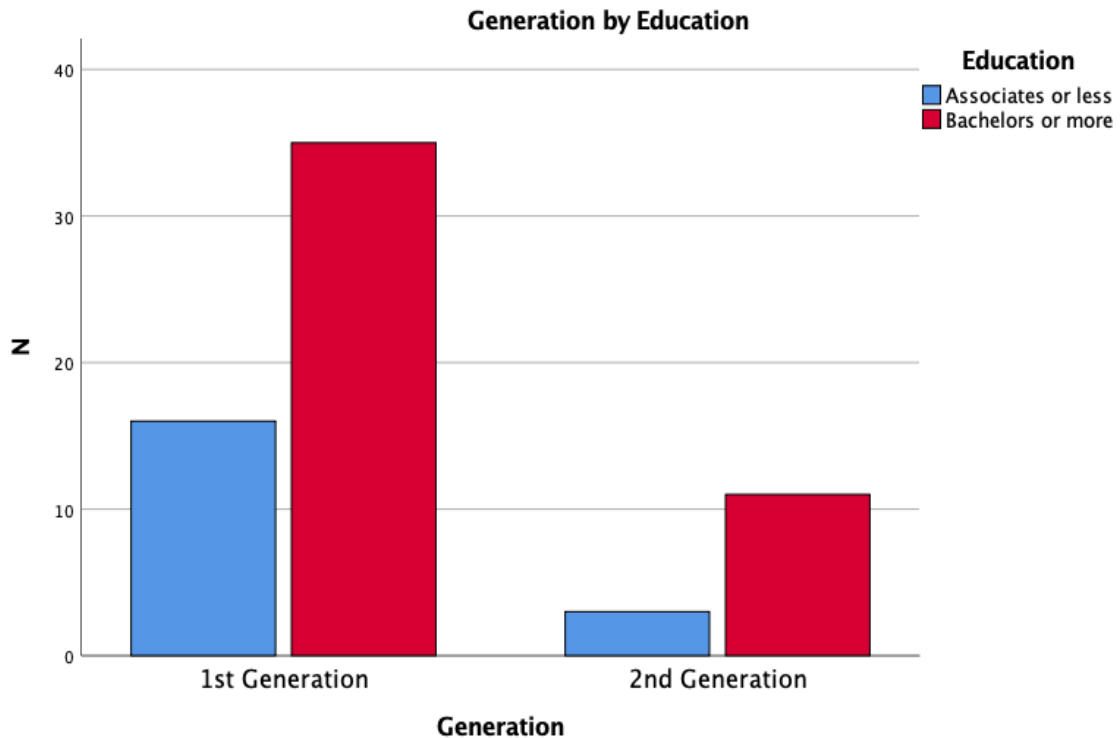


Figure 2. Participants level of education by generations.

A Fisher's exact test was done to compare participants education with generation to determine if the level of education impacted one generation more than the other. Results indicate that 51 (78.4%) of first-generation participants had an associate's or more. A chi-square analysis revealed a statistically significant correlation ($p = .003$).

When the question was asked, "If given a chance, would you consider participating in a clinical research study?" 26 (40%) individuals from Generation 1 said "yes" and 25 (38%) said "no." In addition, seven (50%) from Generation 2 said "yes," and the other 50% said "no." Furthermore, when participants were asked, "Would you take a drug that was not tested in animal or humans?" 47 (90%) respondents declined.

When the participants were asked "How would you like to be informed about clinical trials?" a majority 44 (67.7%) of the respondents from Generation 1 preferred to be informed through a physician and seven (10.8%) from other forms. There were eight (12.3%) respondents

from Generation 2 who also preferred to be informed through a physician and six (9.2%) individuals who would like to be informed through other ways. chi-square analysis was conducted and a statistical significance was determined. It should also be noted that this significance had a medium effect size according to the Cramer's V analysis. $\chi^2(1) = 5.826, p = 0.016, \phi = 0.299$. This clearly indicates that the majority of first-generation participants wanted to be informed about clinical trials through a physician (see Table 4).

Table 4

How Participants Preferred to Be Informed by Generation

Participants informed by	First Generation	Second Generation
Physician	44 (67.7%)	8 (12.3%)
Other	7 (10.8%)	6 (9.2%)

Chapter 5: Discussion

The purpose of this study was to identify any differences in willingness to participate in clinical trials between first- and second-generation Arab American immigrants. The results indicate more first-generation ($n = 51$) Arab Americans responded to the survey than second-generation ($n = 14$) Arab Americans. Perhaps first-generation immigrants are trying hard to adapt to new cultures and do all the necessary tasks to fit in; however, it is difficult to make the assumption that one generation is more willing to participate in clinical trials than the other with this small population sample. An equal and larger sample size is needed in order to make an accurate comparison.

The current survey was emailed to both males and females at the Islamic center. However, more female participants responded to the survey. There is an improvement in the number of female participants in clinical trials from past decades (Scott et al., 2018). Furthermore, despite the fact that the Arab population is the fastest growing population in the United States, they continue to be underrepresented when it comes to clinical research, especially Arab women. Arab immigrants in the United States struggle to acculturate successfully because of their culture and beliefs.

The survey results also revealed that a majority of the participants were between the age of 18 and 34 for first generation; perhaps if we had more participants that were 35 or older for first generation, they may prove to have a different result. Older participants may be more willing to participate in clinical trials, especially if it came from their physician, where they have better trust and understanding of the clinical research. On the contrary, the present age group from first generation who did respond to the survey may have incorrectly answered the

questions. For example, when participants were asked “What are clinical trials?” 11% said they were not sure.

The majority ($n = 63$; 97%) of the participants were Muslim, with the exception of two participants: one Protestant Christian and one participant who preferred not to answer. The results are within the expected outcome considering the survey was conducted at a mosque, which is where Muslims practice their religion. However, the Protestant Christian could have been an employee at the Islamic center, as you do not have to be a Muslim to be employed at the center. Furthermore, 41 (61.5%) of the participants were of Middle Eastern descent. The geographical location of where the study was conducted may have impacted the results. Dearborn city is a home to one of the largest Middle Eastern Muslim population in the United States.

A correlational assessment was conducted to compare generations and participants’ knowledge of clinical research. However, the question about the participants’ knowledge had too many factors for a small sample size. Therefore, the categories had to be re-grouped into two groups: “not knowledgeable” or “somewhat knowledgeable” about clinical research (Table 3). Twenty-two (33.8%) respondents from Generation 1 had at least little knowledge about clinical trials, while contrarily, 29 (44.6%) of first generation had no knowledge of clinical trials. In addition, seven (10.8%) respondents from Generation 2 had at least a little knowledge about clinical research and seven (10.8%) were not knowledgeable about clinical research. A chi-square analysis revealed a statistically significant result at $p = .004$ (Figure 2). Similarly, education had to be re-grouped into two groups; associate’s or less and bachelor’s or more, because of the low number of participants in this survey. The results revealed that 35 (68.6%) of first-generation respondents had a bachelor’s or more and 11 (78.6%) of the second-generation respondents that also had a Bachelor’s or more with a statistically significant $p = .003$ (Figure 3).

This indicates that this particular group that was surveyed was well educated. These findings indicate that despite the fact that this particular population sample was well educated, the participants may not be knowledgeable about clinical research. Other literature shows that one of the major reasons for lack of participation in clinical trials among Arab populations is not being informed or knowledgeable about research (Tohid, et al., 2017). Furthermore, when participants were asked how they would like to be informed about clinical research, 44 (67.7%) of first-generation respondents and eight (12.3%) respondents from the second generation said through a physician (Figure 4). This indicates that if information is received from a physician, it may increase their chance of participation in clinical trials: “Patients’ decisions regarding trial participation may be influenced by the information they receive” (Moorcraft et al., 2016, P.2).

Of the sixty-five surveyed participants, the major reason for willingness to participate in clinical research was to help future generations ($n = 28$; 43%). These findings are consistent with studies conducted by Moorcraft et al. (2016), which revealed the major reasons that influence a patient’s willingness to participate in clinical research is to benefit others. Additionally, the major reason for not willing to participate was out of concern that it would not be safe ($n = 29$; 44.6%). It is challenging when it comes to recruiting subjects to participate in clinical trials as fear and mistrust exist in the Arab population (Tohid, et al., 2017).

In a previous study conducted by Tohid et al. (2017), where 2,379 Arab participants were studied in Doha, Qatar to assess the attitudes towards participation in clinical research, their findings revealed three main reasons for declining to participate in clinical research: time constraint, fear, and lack of being informed.

The overall study may have obtained better results if there had been a tutorial explaining the study prior to taking the survey online, or if it was given in-person, with one-on-one

instructions. In addition, some of the questions in the survey could have been improved or eliminated, such as marital status, did not have any value in the survey. Additionally, the question about reasons why you might agree or not agree to participate in clinical research could have been combined into one question.

To improve participation among immigrants and minorities in clinical trials, researchers should invest in strategies to overcome cultural barriers that exist in clinical research and provide future interventions.

Limitations of the Study:

- The sample size was small and uneven between the generational groups.
- Due to the low response by both generations, some variables had to be collapsed for analyses.

Chapter 6: Conclusion

In summary, the overall study was conducted among 65 participants to identify if first-generation immigrants were more willing than second-generation immigrants to participate in clinical trials. The survey consisted of 18 questions in all. Our study findings conclude that no differences were seen between generational willingness to participate in clinical research. This is likely due to the small number of second-generation respondents. There were trends seen, however, as it appears that Muslim women were more willing to answer survey questions than Muslim men. The impact of this differential response rate on the survey results is unknown. It is also unknown whether face-to-face surveys might have improved response rate overall and the response rate of men in particular. Additional research is warranted. Our hypothesis that first-generation immigrants are more willing than second-generation immigrants to participate in clinical trials requires a larger and sample size in with better representation from both generations.

References

- Asi, M., & Beaulieu, D. (2013). *Arab households in the United States: 2006-2010*. (American Community Survey Brief #10-20). Washington, DC: U.S. Department of Commerce. Retrieved from <http://www.census.gov/prod/2013pubs/acsbr10-20.pdf>
- Albrecht, T. L., Eggly, S. S., Gleason, M. E., Harper, F. W., Foster, T. S., Peterson, A. M., ... Ruckdeschel, J. C. (2008). Influence of clinical communication on patients' decision making on participation in clinical trials. *Journal of Clinical Oncology*, *26*(16), 2666-2673. doi:10.1200/jco.2007.14.811
- Bourque, F., Malla, A., & Van der Ven, E. (2011). Exploring sources of variation in the risk for psychotic disorders among first- and second-generation migrants. *International Clinical Psychopharmacology*, *26*, pp.e66-e67. doi:10.1097/01.yic.0000405745.81951.a9
- Brown, D., Cowdery, J., Jones, T., Langford, A., Gammage, C., & Jacobs, T. (2015). Adolescent knowledge and attitudes related to clinical trials. *Clinical Trials: Journal Of The Society For Clinical Trials*, *12*(3), pp.212-214. doi: 10.1177/1740774515571443
- Camarota, S., & Zeigler, k. (2014). Author: Steven A. Camarota. Retrieved from <https://cis.org/Camarota>
- Chu, S., Kim, E., Jeong, S., & Park, G. (2015). Factors associated with willingness to participate in clinical trials: a nationwide survey study. *BMC Public Health*, *15*(1), 1-8. doi: 10.1186/s12889-014-1339-0
- George, S., Duran, N., & Norris, K. (2014). A systematic review of barriers and facilitators to minority research participation among African Americans, Latinos, Asian Americans, and Pacific Islanders. *American Journal of Public Health*, *104*(2), pp.16-31. <http://dx.doi.org/10.2105/AJPH.2013.301706>

- Haddad, L., Al-Bashaireh, A., Ferrell, A., & Ghadban, R. (2017). Effectiveness of a Culturally-Tailored Smoking Cessation Intervention for Arab-American Men. *International Journal of Environmental Research and Public Health*, 14(4), 411. doi:10.3390/ijerph14040411
- Han, H., Kang, J., Kim, K. B., Ryu, J. P., & Kim, M. T. (2006). Barriers to and strategies for recruiting Korean Americans for community-partnered health promotion research. *Journal of Immigrant and Minority Health*, 9(2), 137-146. doi:10.1007/s10903-006-9022-x
- Hershenberg, R., Drabick, D. A., & Vivian, D. (2012). An opportunity to bridge the gap between clinical research and clinical practice: Implications for clinical training. *Psychotherapy*, 49(2), 123-134. <http://dx.doi.org/10.1037/a0027648>
- Jaber, L. A. (2003). Barriers and strategies for research in Arab Americans. *Diabetes Care*, 26(2), 514-515. doi:10.2337/diacare.26.2.514
- Kolankiewicz, L. (2015). Immigration, Population Growth, and the Environment. Retrieved from <https://cis.org/Report/Immigration-Population-Growth-and-Environment>
- López, G., Bialik, K., & Radford, J. (2018). *Key findings about U.S. immigrants*. Location: Pew Research Center. Retrieved from: at: <http://www.pewresearch.org/fact-tank/2018/11/30/key-findings-about-u-s-immigrants/>
- Moffett, D. (2019). Would you be considered a first or second generation immigrant?. Retrieved from <https://www.thoughtco.com/first-generation-immigrant-defined-1951570>

Moorcraft, S., Marriott, C., Peckitt, C., Cunningham, D., Chau, I., Starling, N., Watkins, D., &

Rao, S. (2016). Patients' willingness to participate in clinical trials and their views on aspects of cancer research: results of a prospective patient survey. *Trials*, 17(1).

Nowak, M. (2018). Immigration and U.S. population growth: An environmental perspective: |

Negative population growth. Retrieved from: <http://www.npg.org/special-report/immigration-and-u-s-population-growth-an-environmental-perspective.html>

OECD. (2016). Change between 2006 and 2015 in the percentage of second- and first-generation immigrant students. *PISA 2015 Results (Volume I)*. doi:10.1787/9789264266490-graph89-en

Salman, A., Nguyen, C., Lee, Y., & Cooksey-James, T. (2016). A review of barriers to minorities' participation in cancer clinical trials: Implications for future cancer research.

Journal of Immigrant and Minority Health, 18(2), 447-453.

doi:<http://dx.doi.org/10.1007/s10903-015-0198-9>

Scott, P. E., Unger, E. F., Jenkins, M. R., Southworth, M. R., McDowell, T., Geller, R. J., . . .

Woodcock, J. (2018). Participation of women in clinical trials supporting

FDA approval of cardiovascular drugs. *Journal of the American College of*

Cardiology, 71(18), 1960-1969. doi:10.1016/j.jacc.2018.02.070

Smith, A., Agar, M., Delaney, G., Descallar, J., Dobell-Brown, K., & Grand, M. et al. (2017).

Lower trial participation by culturally and linguistically diverse (CALD) cancer patients

is largely due to language barriers. *Asia-Pacific Journal of Clinical Oncology*, 14(1),

52-60. doi: 10.1111/ajco.12818

Tohid, H., Choudhury, S. M., Agouba, S., Aden, A., Ahmed, L. H., Omar, O., . . . Taheri, S. (2017). Perceptions and attitudes to clinical research participation in

Qatar. *Contemporary Clinical Trials Communications*, 8, 241-247.

United Nations. (2000). Handbook on Census Management for Population and Housing Censuses., doi:10.18356/f9cb017b-en

Wallington, S., Luta, G., Noone, A., Caicedo, L., Lopez-Class, M., Sheppard, V., Spencer, C., & Mandelblatt, J. (2011). Assessing the awareness of and willingness to participate in cancer clinical trials among immigrant Latinos. *Journal of Community Health*, 37(2), pp. 335-343.

APPENDICIES

Appendix A: Response Letter from EMU Human Subject Review Committee

Mar 21, 2018 10:49 AM EDT

Aisha Farha

Eastern Michigan University, School of Health Sciences

Re: Initial - UHSRC-FY17-18-328 Are First Generation Immigrants More Inclined to Participate in Clinical Research Dear Aisha Farha:

The Eastern Michigan University Human Subjects Review Committee has rendered the decision below for Are First Generation Immigrants More Inclined to Participate in Clinical Research.

Decision: Minor Stipulations

Findings: Please respond to all comments in the application. Click "reply" to register and save your response. For changes in any of the supplemental documents, make changes in Track Changes mode or highlight all changes in the revised documents so that they can be easily seen. If you make any additional changes or do not address all of the comments, please include a letter explaining the changes and why you did not address specific comments.

Please make any required revisions to the Cayuse IRB application and study documents and upload the revised documents in the Cayuse IRB application. Once your revisions are complete, the UHSRC will review your revisions and render a decision.

You are not approved to conduct human subject research on this study. You may not begin your research until you receive an approval letter.

Please contact human.subjects@emich.edu with any questions or concerns. Sincerely,
Eastern Michigan University Human Subjects Review Committee

Appendix B: Approval Letter after Sample Size Modification

May 16, 2018 9:53 AM EDT

Aisha Farha

Eastern Michigan University, School of Health Sciences

Re: Modification - UHSRC-FY17-18-328 Are First Generation Immigrants More Inclined to Participate in Clinical Research

Dear Aisha Farha:

The Eastern Michigan University Human Subjects Review Board has rendered the decision below for Are First Generation Immigrants More Inclined to Participate in Clinical Research.

Decision: Exempt

Findings:

Contact human.subjects@emich.edu with questions and concerns.

Sincerely,

Eastern Michigan University Human Subjects Review Committee

Appendix C: Informed Consent Form (English Version)

RESEARCH @ EMU**Informed Consent Form**

Project Title: Immigrant status and participation in clinical research
Principal Investigator: Aisha Farha at Eastern Michigan University

Invitation to participate in research

You are invited to participate in a research study. In order to participate, you must be 18 years of age or older. Participation in research is voluntary. Please ask any questions you have about participation in this study.

What is this study about?

The objective of this study is to identify the willingness of immigrants to participate in clinical research.

What will happen if I participate in this study? Participation in this study involves answering questions related to research, which will help me understand -immigrants understanding of and their attitude towards research.

What are the expected risks for participation?

There are no expected physical or psychological risks to participation.

Are there any benefits to participating?

You will not directly benefit from participating in this research.

How will my information be kept confidential?

As we are not collecting subjects' names on the survey sheet, your information will therefore be confidential. If you answer the questions verbally, the questioner will make no notation of your identity on the survey sheet.

Storing study information for future use

We WILL NOT store your information to study in the future. Your information will be labeled with a code and not your name. Your information will be stored in a password-protected or locked file.

What are the alternatives to participation?

The alternative is not to participate.

Are there any costs to participation?

Participation will not cost you anything.

Will I be paid for participation?

You will not be paid to participate in this research study.

Study contact information

If you have any questions about the research, you can contact the Principal Investigator, Afarha4@emich.edu. You may also contact my advisor, Dr. Irwin Martin at Eastern Michigan University, imartin2@emich.edu

For questions about your rights as a research subject, contact the Eastern Michigan University Human Subjects Review Committee at human.subjects@emich.edu or by phone at 734-487-3090.

Voluntary participation

Participation in this research study is your choice. You may refuse to participate at any time, even after signing this form, without repercussion. You may choose to leave the study at any time without repercussion.

Statement of Consent

I have read this form. I have had an opportunity to ask questions and am satisfied with the answers I received. I give my consent to participate in this research study.

Signatures:

Signature of Subject

Date

I have explained the research to the subject and answered all his/her questions. I will give a copy of the signed consent form to the subject.

Name of Person Obtaining Consent

Signature of Person Obtaining Consent

Date

Appendix D: Informed Consent Form (Arabic Version)

موافقة مسبقة

وضع المهاجرين والمشاركة في البحوث السريرية

دعوة للمشاركة في البحث
أنت مدعو للمشاركة في دراسة بحثية. من أجل المشاركة ، يجب أن يكون عمرك ١٨ عامًا أو أكثر. المشاركة في البحوث طوعية. يرجى طرح أي أسئلة لديك عن المشاركة في هذه الدراسة

ما هي هذه الدراسة حول؟
الهدف من هذه الدراسة هو تحديد رغبة المهاجرين في المشاركة في البحوث السريرية

ما هي المخاطر المتوقعة للمشاركة؟

لا توجد مخاطر جسدية أو نفسية متوقعة للمشاركة

هل هناك أي فوائد للمشاركة؟

لن تستفيد بشكل مباشر من المشاركة في هذا البحث

كيف سيتم الحفاظ على سرية معلوماتي؟
نظرًا لأننا لا نجمع أسماء المواضيع على ورقة الاستبيان ، فستكون معلوماتك سرية. إذا أجبت على الأسئلة شفهيًا ، لن نقوم
السائل بتدوين هويتك على ورقة الاستبيان
تخزين معلومات الدراسة للاستخدام في المستقبل

لن نقوم بتخزين معلوماتك للدراسة في المستقبل. ستتم تسمية معلوماتك برمز وليس باسمك. سيتم تخزين المعلومات
الخاصة بك في ملف محمي بكلمة مرور أو مؤمن
هل هناك أي فوائد للمشاركة؟
لن تستفيد بشكل مباشر من المشاركة في هذا البحث

ما هي بدائل المشاركة؟

البديل هو عدم المشاركة

هل هناك أي تكاليف للمشاركة؟

المشاركة لن تكلفك شيئًا

هل سأدفع مقابل المشاركة؟

لن يتم الدفع لك للمشاركة في هذه الدراسة البحثية

دراسة معلومات الاتصال

يمكنك Afarha4@emich.edu ، إذا كان لديك أي أسئلة حول البحث ، يمكنك الاتصال علىالباحث الرئيسي imartin2@emich.edu ، أيضاًالاتصال بمستشاري ، الدكتور إيروين مارتن في جامعة ميتشيجان الشرقية

والمشاركة الطوعية

المشاركة في هذه الدراسة البحثية هي اختياريك. يمكنك رفض المشاركة في أي وقت ، حتى بعد التوقيع على هذا النموذج ، دون أي تداعيات. يمكنك اختيار ترك الدراسة في أي وقت دون أي تداعيات

بيان الموافقة

لقد قرأت هذا النموذج. لقد أتيت لي الفرصة لطرح الأسئلة وأنا راض عن الإجابات التي تلقيتها. أعطي موافقتي للمشاركة في هذه الدراسة البحثية
التوقيعات:

التوقيع على تاريخ الموضوع

لقد شرحت البحث لهذا الموضوع وأجبت على جميع أسئلته. سوف أعطي نسخة من نموذج الموافقة الموقعة لهذا الموضوع

اسم الشخص الحاصل على الموافقة

توقيع الشخص الحاصل على تاريخ الموافقة
والمشاركة الطوعية

المشاركة في هذه الدراسة البحثية هي اختياريك. يمكنك رفض المشاركة في أي وقت ، حتى بعد التوقيع على هذا النموذج ، دون أي تداعيات. يمكنك اختيار ترك الدراسة في أي وقت دون أي تداعيات

Appendix E: Survey Questions in English

Survey Questions: Please answer to the best of your ability.

- 1) How knowledgeable are you about clinical research?
 - a) Not at all knowledgeable
 - b) A little knowledgeable
 - c) Somewhat knowledgeable
 - d) Completely knowledgeable

- 2) Clinical research or clinical trials are:
 - a) Scientific investigations using humans to study treatment of human disease
 - b) Scientific investigations using animals to study treatment of human disease
 - c) Scientific investigations using laboratory studies to study treatment of human disease
 - d) Not sure

- 3) If given a chance, would you consider participating in a clinical research study?
 - a) Yes
 - b) No
 - c) Not sure

- 4) You might agree to be in a clinical research study:
 - a) If you get paid
 - b) To help future generations
 - c) Because it might be an interesting thing to do
 - d) To get help with your illness

- 5) You might not agree to participate in a research study:
 - a) Because you do not want to be used as a guinea pig in research
 - b) Because you do not know if it would be safe
 - c) As you simply prefer not to
 - d) Because you are concerned about taking an experimental drug

- 6) Would you take a drug that was not tested in animal or humans?
 - a) Yes
 - b) No

- 7) How would you like to be informed of a clinical research study you might be appropriate for?
 - a) From your physician
 - b) By reading an advertisement
 - c) From a government list
 - d) From a posting at a community site
 - e) Through Facebook or other social media

- 8) Where do you think clinical research is conducted? (Note all that apply)
 - a) Hospitals

- b) University Medical Centers
- c) Clinics
- d) Private Physician Office
- e) Not sure

The following questions are for classification purposes only. As a reminder, no personal information is identifiable.

- 9) Your age:
- a) 18 - 24 years
 - b) 25 - 34 years
 - c) 35 - 65 years
 - d) 65 years or older
- 10) Gender?
- a) Male
 - b) Female
 - c) Other/prefer not to answer
- 11) What is your highest level of education?
- a) Less than High School
 - b) High School
 - c) Bachelor's degree
 - d) Master's degree or greater
- 12) What is your marital status?
- a) Married
 - b) Single
 - c) Prefer not to answer
- 13) How long have you lived in the United States?
- a) <5 years
 - b) 5-10 years
 - c) >10 years
 - d) You do not live in the US
- 14) What language do you speak at home?
- a) English
 - b) Arabic
 - c) Spanish
 - d) French
 - e) other
- 15) How fluent are you in English?
- a) Read, write and speak well
 - b) Understand conversational English
 - c) Do not speak English

16) What is your or your parents' country of origin?

- a) US
- b) Yemen
- c) Iraq
- d) Other Middle Eastern
- e) Other

17) How long have your parents' been a resident in the United States?

- a) <5 years
- b) 5-10
- c) >10 years
- d) Your parents do not live in the US

18) What religion does your family practice?

- a) Protestant Christian
- b) Catholic Christian
- c) Islam
- d) Judaism
- e) Buddhism
- f) Other or Prefer not to answer

Appendix F: Survey Questions in Arabic

أسئلة الاستطلاع: الرجاء أسئلة الاستطلاع: الرجاء الإجابة على أفضل ما في قدر

ما مدى معرفتك بشأن البحث السريري؟
 أ) ليس على الإطلاق المعرفة
 ب) القليل من المعرفة
 ج) على دراية إلى حد ما
 د) على دراية

:البحوث السريرية أو التجارب السريرية هي ()
 أ) التحقيقات العلمية باستخدام البشر لدراسة علاج الأمراض البشرية
 ب) التحقيقات العلمية باستخدام الحيوانات لدراسة علاج الأمراض البشرية
 ج) التحقيقات العلمية باستخدام الدراسات المخبرية لدراسة علاج الأمراض البشرية
 د) غير متأكد

إذا أتحت لك الفرصة ، فهل تفكر في المشاركة في دراسة بحثية إكلينيكية؟
 أ) نعم
 ب) لا
 ج) غير متأكد

:قد توافق على أن تكون في دراسة بحثية إكلينيكية
 أ) إذا كنت تحصل على أموال
 ب) مساعدة الأجيال القادمة
 ج) لأنه قد يكون شيئاً مثيراً للاهتمام
 د) للحصول على مساعدة بشأن مرضك
 أ) لأنك لا تريد أن تستخدم كخنزير غينيا في البحث
 ب) لأنك لا تعرف ما إذا كانت آمنة
 ج) كما تفضل ببساطة عدم القيام بذلك
 د) لأنك قلق بشأن تناول عقار تجريبي

:قد لا توافق على المشاركة في دراسة بحثية ()
 أ) لأنك لا تريد أن تستخدم كخنزير غينيا في البحث
 ب) لأنك لا تعرف ما إذا كانت آمنة
 ج) كما تفضل ببساطة عدم القيام بذلك
 د) لأنك قلق بشأن تناول عقار تجريبي

هل تأخذ دواء لم يتم اختباره في الحيوان أو البشر؟
 أ) نعم
 ب) لا

كيف تريد أن تكون على علم بدراسة بحثية سريرية قد تكون مناسبة لها؟

- أ) من طبيبك
- ب) من خلال قراءة الإعلان
- ج) من قائمة الحكومة
- د) من نشر في موقع المجتمع
- ه) من خلال الفيسبوك أو وسائل التواصل الاجتماعي الأخرى

أين تعتقد أن البحوث السريرية تتم؟ (لاحظ كل ما ينطبق)

- أ) المستشفيات
- ب) مراكز الجامعة الطبية
- ج) العيادات
- د) مكتب الطبيب الخاص
- ه) غير متأكد

الأسئلة التالية هي لأغراض التصنيف فقط. كتذكير ، لا يمكن التعرف على أي معلومات شخصية

عمرك :

- أ) من 18 إلى 24 عامًا
- ب) 25 - 34 سنة
- ج) 35 - 65 سنة
- د) 65 سنة أو أكثر

الجنس؟

- ذكر
- ب) أنثى

البعض / يفضل عدم الاجابة

- قل من المدرسة الثانوية
- ب) المدرسة الثانوية
- ج) درجة البكالوريوس
- د) درجة الماجستير أو أكبر

ما هي حالتك الاجتماعية؟

- أ) متزوج
- ب) واحد
- ج) يفضل عدم الإجابة
- ما هو أعلى مستوى تعليمي؟
- أ) أقل من المدرسة الثانوية
- ب) المدرسة الثانوية
- ج) درجة البكالوريوس
- د) درجة الماجستير أو أكبر

ما هي حالتك الاجتماعية؟

- أ) متزوج

ب) واحد
ج) يفضل عدم الإجابة

منذ متى وأنت تعيش في الولايات المتحدة؟

أ) < 5 سنوات

ب) 5-10 سنوات

ج) > 10 سنوات

د) أنت لا تعيش في الولايات المتحدة

ما اللغة التي تتحدثها في المنزل؟

أ) الإنجليزية

ب) العربية

ج) الإسبانية

د) الفرنسية

ه) أخرى

كيف تتقن اللغة الإنجليزية؟

أ) القراءة والكتابة والتحدث بشكل جيد

ب) فهم الإنجليزية للمحادثة

ج) لا تتحدث الإنجليزية

ما هو بلد منشأك أو والدك؟

أ) الولايات المتحدة

ب) اليمن

ج) العراق

د) الشرق الأوسط أخرى

ه) أخرى

منذ متى كان والديك مقيما في الولايات المتحدة؟

أ) < 5 سنوات

ب) 5-10 سنوات

ج) > 10 سنوات

د) لا يعيش والديك في الولايات المتحدة

ما هو الدين الذي تمارسه عائلتك؟ (19)

أ) البروتستانت المسيحي

ب) مسيحي كاثوليكي

ج) الإسلام

د) اليهودية

ه) البوذية

و) أخرى أو تفضل عدم الإجابة

Appendix G: Permission for the Site



March 5, 2018

RE: Aisha Farha

I, Said Mashgari on behalf of Dearborn Community Center/Masjid Alsalam address 3900 Schaefer Rd, Dearborn, MI48126 grant permission for Aisha Farha to conduct the clinical research survey for her thesis requirement at Eastern Michigan University. She will conduct her research titled, "Are First Generation Immigrants More Inclined to Participate in Clinical Research". I understand that Aisha Farha will recruit our clients and conduct interviews at Dearborn Community Center/Masjid Alslam over the next several weeks. We are happy to participate in the study and contribute to this important research.

Best Wishes,

Said Mashgari
Executive Board of Directors

Dearborn Community Center
 3900 Schaefer Rd.
 Dearborn, MI 48126
(313) 999-4358
 (313) 632-1222

