

## ORIGINAL ARTICLE

**Observational Study for Clinical Trials Participation in Malaysia**Sunil Kumar Prajapati<sup>1</sup>, Wing Yin Chin<sup>2</sup>, Jin Yi Choo<sup>2</sup>, Pushpraj S Gupta<sup>1</sup>, Satendra Singh<sup>3</sup>, Promod Kumar Yadav<sup>3</sup><sup>1</sup> Dept. Pharmaceutical science, Sam Higginbottom University of Agriculture, Technology and Sciences, Prayagraj-211007 (U.P.), India<sup>2</sup> Faculty of Pharmacy, AIMST University, Malaysia<sup>3</sup> Dept. of Computational Biology and Bioinformatics, JIBB, Sam Higginbottom University of Agriculture, Technology and Sciences, Prayagraj-211007 (U.P.), India**ABSTRACT**

**Introduction:** This observational study was conducted to assess the knowledge, attitudes, and perceptions (KAP) of Malaysians toward participating in clinical trials. It also aimed to look for factors that will influence people's willingness to participate in trials. We planned and developed future outreach, education tools, and recruitment strategies to increase clinical trial enrolment. **Methods:** A cross-sectional study was carried out on a randomly selected sample of 398 Malaysian literate adults. An online questionnaire was created and distributed to the respondents. Descriptive statistics were presented in the form of frequency and percentages. The chi-square test was employed to find the association between independent variables. **Results:** The majority had good knowledge (61.3%) and high awareness (88.7%) of clinical trials. However, most of them were not willing to take part in a clinical trial if they were assigned to a group of unlicensed drugs (90.2%) or randomly assigned (66.1%). The main reasons for participating in trials were recommendations from doctors (46.5%) and the potential for their own benefit (45.7%). Younger age was positively associated with the necessity and confidentiality of clinical trials. Most respondents indicated negative perceptions towards the safety of clinical trials regardless of demographic variables. **Conclusion:** We gained a better understanding of Malaysian people who are potential participants in a future clinical trial. These findings could help clinical researchers improve their understanding of the participants and develop effective outreach strategies for clinical trial recruitment and retention.

Malaysian Journal of Medicine and Health Sciences (2024) 20(2): 26-33. doi:10.47836/mjmhs.20.2.5

**Keywords:** Knowledge, Attitudes, Perception, Clinical Trial, Participation**Corresponding Author:**

Sunil K. Prajapati, M.Pharm

Email: clinical.sunil@gmail.com

Tel: +91 6392097909

**INTRODUCTION**

Clinical trials, also known as interventional studies, are the cornerstone of medical advancement. According to the World Health Organization (WHO), "A clinical trial is any research study that prospectively assigns human participants or groups of humans to one or more health-related interventions to evaluate the effects on health outcomes"(1). Clinical trial ensures the safety and efficacy of new drugs or devices used to treat human diseases that are either newly discovered or already exist. It also highlights the best medical treatment that best serves a particular population (2).

The significance of expanding medical knowledge is widely acknowledged by both the medical community and the general population (3). Despite these facts and the overall acceptance of the advantages of clinical trials,

the global rates of clinical trial participation remain low. Globally, the number of participants in clinical trials has decreased from 110,000 to 50,000 from 2015 to 2019, while among these participants, only 11% of Asian ethnicity take part in the clinical trials (4). This issue is of great concern, especially in Malaysia. Malaysia placed 44th in enrolling clinical trial participants between 2015-2016, which occupies only 0.29% (n=382) of the total participants (N=131,749) worldwide for these two years (i.e., 2015 and 2016) (5).

One of the most crucial stages that determine the success of a clinical trial is participant recruitment. A clinical study may be unreliable if its enrolment target is not met or if there are too many dropouts. This can be a hard nut to crack. When there is a lack of volunteer participation, the sponsor may increase funds allocated to the study or broaden the study sites (perhaps in new countries, with associated expensive protocol amendments and delays in further research). As a result, in order to manage the funds at hand more effectively, it is occasionally necessary to call off certain planned tests. Consequently, certain endpoints might not have

enough sample size to reach an unambiguous evidence-based conclusion on the efficacy and safety of clinical interventions. In light of this, a low recruitment rate may lead to clinical trials becoming more expensive and time-consuming and eventually may fail to answer the main research question.

Numerous researchers have investigated the patients' attitudes and willingness to participate in clinical trials. However, the majority of their work was focused on specific diseases or racial groups in other countries (6–10). Such data are lacking from healthy volunteers in Malaysia who represent the potential participants for future clinical trials. There is a need for additional study into the factors that affect society as a whole, including the behaviours that discourage people from signing up for clinical trials. Therefore, research was carried out to assess the knowledge, attitudes and perceptions of Malaysians about participation in clinical trials. The findings of this study may be used to determine the factors influencing willingness to take part in clinical trials, which will help in the development of future outreach initiatives to boost clinical trial enrolment across the country.

## **MATERIALS AND METHODS**

A cross-sectional survey among Malaysian literate adults, was carried out from March to June 2022. Data was collected using an online questionnaire developed by means of Google Forms in the English language. The questionnaire was divided in 4 sections for estimating Demographic details, Knowledge, Attitudes and Perception. It was disseminated to participants through email and social media platforms such as WhatsApp, Facebook and Instagram throughout Malaysia. A non-probability convenient sampling technique was employed for the recruitment of study participants/respondents. As per inclusion criteria, all participants who were willing to participate, those whose age was 18 years and above, those who were Malaysian citizens and those who were able to read and comprehend basic English were included. Individuals not falling on inclusion criteria were excluded from this study. The sample size was calculated to be 385 via the Raosoft Sample-Size Calculator to achieve a confidence level of 95% with a margin of error of 5%, a response distribution of 50% and a population size of 32.7 million for the present survey. 385 participants were the minimum number of necessary sample size to meet the desired statistical constraints. However, 398 participants responded with all fulfilled domains of the questionnaire which was included in the result estimation to oblige all 398 participants' responses.

### **Validity of the Study Tool**

Two faculty members were requested to review the questionnaire for its face and content validity. The double-barrel questions were taken out and the items

that need to be excluded were pointed out. Removal of repetition was done, and the discrepancies were rectified. Long statements were rephrased into short, clear, and direct sentences. Reliability assessment was done by Cronbach's alpha and the acceptable level was set at >0.7.

### **Data Collection**

The online questionnaire was electronically shared. A consent statement was included at the start of the questionnaire and the data was collected voluntarily. A short description of the study project's aims and objectives was provided before filling out the survey. All participants had to give their willingness to participate before accessing the detailed questionnaire. All participants were allowed to withdraw anytime if they did not want to continue. The online questionnaire consists of four sections; (a) basic socio-demographic information; (b) knowledge and awareness about clinical trials; (c) attitudes towards participating in clinical trials; and (d) perceptions towards clinical trials. The knowledge and awareness were assessed with Multiple-Choice Questions (MCQs) in the questionnaire. The subjects were required to select the best answer based on their knowledge. A score of one was given for the correct answer while a score of zero was given for the wrong answer. The scores of the whole section were categorized, based on Bloom's cut-off point, as good if the score was between 80 and 100%, moderate if the score was between 60 and 79%, and poor if the score was less than 60%. The attitudes and perceptions of clinical trials were assessed using 5-point Likert scale such as strongly agree, agree, neutral, disagree and strongly disagree on a list of items. The perception items were categorized into domains of necessity, safety, logistics and confidentiality based on the literature. (11) The scores for agree and strongly agree for all the subjects were summarized and analysed.

### **Statistical Analysis**

SPSS version 26.0 was used to analyse the data. Frequency and percentages were computed for the categorical variables. The chi-square test was used for comparing between different categorical variables. All p-values <0.05 were considered significant. The reliability of the knowledge, attitude and practice section of the questionnaire was tested using Cronbach's alpha.

### **Ethical Approval**

The data collection process adheres to the institutional and national ethical guidelines and is in accordance with the Helsinki Declaration. Data confidentiality and anonymity were maintained. The study was conducted after obtaining ethical approval from the AIMST University Human Ethics Committee (AUHEC). This study was approved by AIMST University Human and Animal Ethics Committee (AUHAEC) of Faculty of Pharmacy with Ref No: AUHEC/FOP/2022/12.

## RESULTS

A total of 398 respondents were included in the study and all of them had answered all the questions in the questionnaire. The demographic details of section I in questionnaire of the participants are shown in Table I. More than half (244 out of 398, 61.3%) of the respondents had good knowledge of clinical trials; around 28.4% of respondents (113 out of 398) had moderate knowledge of clinical trials and only 10.3% (41 out of 398) of respondents had poor knowledge of clinical trials. Moreover, when respondents asked whether they had ever heard about clinical trials, 88.7% (353 out of 398) of respondents answered in the affirmative. This is considered are awareness.

Based on Table II, awareness of clinical trials was significantly more prevalent among 18-29 years of age, students or employed respondents, who were more

**Table I: General Characteristics of Participants (n = 398)**

Variables	Categories	n	%
Age (years)	18-29	186	46.7
	30-49	176	44.2
	50-65	29	7.3
	Above 65	7	1.8
Gender	Male	176	44.2
	Female	222	55.8
Race	Malay	178	44.7
	Chinese	173	43.5
	Indian	47	11.8
Family status	Single	249	62.6
	Married	144	36.2
	Divorced	2	0.5
	Widowed	3	0.8
Education level	Primary school	14	3.5
	Secondary school	82	20.6
	Pre-university	23	5.8
	Diploma/Degree	279	70.1
Employment status	Employed	220	55.3
	Housewife	12	3.0
	Student	139	34.9
	Unemployed	14	3.5
	Others	13	3.3
Household income (monthly)	Below RM 2,000 / USD 430	57	14.3
	RM 2,000 – RM 2,999 / USD 430 – USD 643	48	12.1
	RM 3,000 – RM 3,999 / USD 644 – USD 858	87	21.9
	Above RM 4,000 / USD 858	206	51.8
Living areas/regions	Metropolitan cities	188	47.2
	Small cities	149	37.4
	Rural areas	61	15.3
Living style	Alone	40	10.1
	With friends	36	9.0
	With partners	16	4.0
	With family	306	76.9

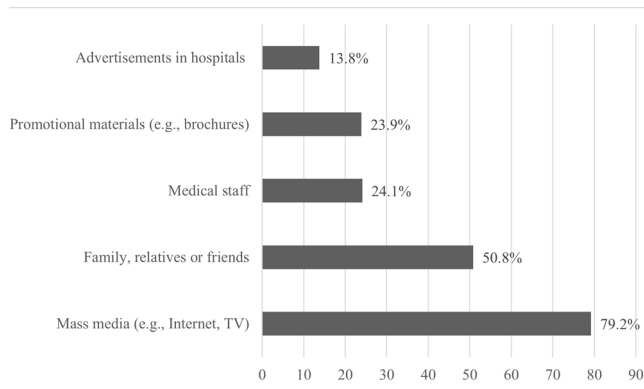
**Table II: Respondents' Awareness of Clinical Trials (n = 398)**

Variables	Yes n (%)	$\chi^2$	p
Age (years)		66.521	<0.001
18-29	182 (97.8)		
30-49	154 (87.5)		
50-65	16 (55.2)		
Above 65	1 (14.3)		
Gender		10.404	0.006
Male	146 (83.0)		
Female	207 (93.2)		
Race		25.467	<0.001
Malay	159 (89.3)		
Chinese	163 (94.2)		
Indian	31 (66.0)		
Family status		42.018	<0.001
Single	237 (95.2)		
Married	115 (79.9)		
Divorced	1 (50.0)		
Widowed	0 (0.0)		
Education level		54.266	<0.001
Primary school	3 (21.4)		
Secondary school	66 (80.5)		
Pre-university	22 (95.7)		
Diploma/Degree	262 (93.9)		
Employment status		71.354	<0.001
Employed	194 (88.2)		
Housewife	5 (41.7)		
Student	138 (99.3)		
Unemployed	6 (42.9)		
Others	10 (76.9)		
Household income		11.193	0.083
Below RM 2,000	46 (80.7)		
RM 2,000 – RM 2,999	41 (85.4)		
RM 3,000 – RM 3,999	75 (86.2)		
Above RM 4,000	191 (92.7)		
Living areas/regions		33.324	<0.001
Metropolitan cities	178 (94.7)		
Small cities	135 (90.6)		
Rural areas	40 (65.6)		
Living style		10.220	0.116
Alone	32 (80.0)		
With friends	35 (97.2)		
With partners	15 (93.8)		
With family	271 (88.6)		

highly educated and were residents of metropolitan cities or small cities based on their pre-specified variables (e.g., age categories).

According to Figure 1, participants responded 'YES' for 'ever heard about clinical trials' considered as awareness. The five most cited methods from which clinical trial awareness had been obtained (in descending order) were mass media, such as the Internet and TV (315 out of 398, 79.2%), family, relatives, or friends (202 out of 298, 50.8%), medical staff (96 out of 398, 24.1%), promotional materials, such as brochures and leaflet (95 out of 398, 23.9%) and advertisements in hospitals (55 out of 398, 13.8%).

Section III of questionnaire estimated Attitudes Towards Participating in Clinical Trials. Based on Table III, when asked about the likelihood of taking part in a clinical trial, 42.2% (168 out of 398) respondents indicated that they would be very likely or likely to participate in a clinical trial if they were healthy without any disease. On the other hand, 49.5% (197 out of 398) of respondents were likely to participate if they were diagnosed with a disease and the initial treatment failed. In cases where



**Figure 1: Sources of Information Regarding Clinical Trials**

**Table III: Respondents' Attitudes Towards Participating in Clinical Trials (n = 398)**

Situations	n	%
Healthy without any disease		
Very likely (5)	33	8.3
Likely (4)	135	33.9
Neutral (3)	80	20.1
Unlikely (2)	134	33.7
Very unlikely (1)	16	4.0
Diagnosed with a disease and initial treatment failed		
Very likely (5)	76	19.1
Likely (4)	197	49.5
Neutral (3)	89	22.4
Unlikely (2)	25	6.3
Very unlikely (1)	11	2.8
Assigned to conventional drug		
Very likely (5)	136	34.2
Likely (4)	178	44.7
Neutral (3)	63	15.8
Unlikely (2)	17	4.3
Very unlikely (1)	4	1.0
Assigned to newly licensed drug		
Very likely (5)	40	10.1
Likely (4)	160	40.2
Neutral (3)	129	32.4
Unlikely (2)	59	14.8
Very unlikely (1)	10	2.5
Assigned to unlicensed drug		
Very likely (5)	3	0.8
Likely (4)	11	2.8
Neutral (3)	25	6.3
Unlikely (2)	111	27.9
Very unlikely (1)	248	62.3
Randomly assigned		
Very likely (5)	7	1.8
Likely (4)	22	5.5
Neutral (3)	106	26.6
Unlikely (2)	181	45.5
Very unlikely (1)	82	20.6

they were assigned to the group of conventional drugs, the majority (314 out of 398, 78.9%) showed positive attitudes towards participating in clinical trials. Around half (160 out of 398, 40.2%) would likely participate if they were allocated to the group of newly licensed drugs. Most of the respondents were not willing to take part in a clinical trial if they were assigned to the group of unlicensed drugs (359 out of 398, 90.2%) or randomly assigned (263 out of 398, 66.1%).

Table IV displays the results for the six factors that may influence the respondents' willingness to take part in clinical trials. Respondents strongly agreed that recommendations from doctors (185 out of 398,

**Table IV: Factors Influencing Respondents' Willingness to Participate in Clinical Trials (n = 398)**

Factor	n	%
Recommendation from doctors		
Strongly agree (5)	185	46.5
Agree (4)	163	41.0
Neutral (3)	41	10.3
Disagree (2)	5	1.3
Strongly disagree (1)	4	1.0
Access to more information on clinical trials		
Strongly agree (5)	78	19.6
Agree (4)	188	47.2
Neutral (3)	110	27.6
Disagree (2)	17	4.3
Strongly disagree (1)	5	1.3
Potential for own benefit		
Strongly agree (5)	182	45.7
Agree (4)	169	42.5
Neutral (3)	37	9.3
Disagree (2)	5	1.3
Strongly disagree (1)	5	1.3
Potential for others' benefit		
Strongly agree (5)	28	7.0
Agree (4)	65	16.3
Neutral (3)	120	30.2
Disagree (2)	176	44.2
Strongly disagree (1)	9	2.3
Monetary reward / reimbursement		
Strongly agree (5)	26	6.5
Agree (4)	143	35.9
Neutral (3)	90	22.6
Disagree (2)	121	30.4
Strongly disagree (1)	18	4.5
Contribution to science knowledge		
Strongly agree (5)	23	5.8
Agree (4)	66	16.6
Neutral (3)	100	25.1
Disagree (2)	159	39.9
Strongly disagree (1)	49	12.3

46.5%) and the potential for their own benefit (182 out of 398, 45.7%) were the key motivation for taking part in clinical trials. Almost half (188 out of 398, 47.2%) agreed that access to more information on clinical trials could influence their willingness to participate. 35.9% (143 out of 398) of respondents agreed that monetary reward or reimbursement was the influencing factor for participating in clinical trials. Most of the respondents disagreed that contribution to science knowledge (159 out of 398, 39.9%) and the potential of others' benefit (176 out of 398, 44.2%) were the factors that would influence their willingness to participate in clinical trials.

Section IV of questionnaire gathered information regarding participants' perception in terms of 'willingness to participate in clinical trial'. The perception items were grouped into domains of necessity, safety, logistics and confidentiality of clinical trials (Table V). Younger adults were positively associated with the necessity and confidentiality of clinical trials but negatively correlated with the logistics of clinical trials. Those who were highly educated had significantly more positive perceptions towards the safety of clinical trials ( $p < 0.001$ ) than the respondents who were not. Nevertheless, these highly educated respondents perceived a negative view towards the logistics of clinical trials ( $p < 0.001$ ). Besides, significant differences were also observed between residents of metropolitan cities and those of other areas in the domain of safety ( $p < 0.001$ ).

**Table V: Respondents' Perception of Clinical Trials (n = 398)**

Variables	Necessity			Safety			Logistics			Confidentiality		
	Agree / Strongly Agree n (%)	x <sup>2</sup>	p	Agree / Strongly Agree n (%)	x <sup>2</sup>	p	Agree / Strongly Agree n (%)	x <sup>2</sup>	p	Agree / Strongly Agree n (%)	x <sup>2</sup>	p
Age (years)		13.905	0.031		8.640	0.195		36.712	<0.001		36.255	<0.001
18-29	171 (92.4)			29 (15.7)			7 (3.8)			45 (24.2)		
30-49	162 (92.0)			44 (25.0)			16 (9.1)			17 (9.7)		
50-65	21 (72.4)			3 (10.3)			2 (6.9)			0 (0.0)		
Above 65	5 (71.4)			1 (14.3)			1 (14.3)			1 (14.3)		
Education level		15.308	0.018		27.790	<0.001		33.364	<0.001		4.837	0.565
Primary school	9 (64.3)			0 (0.0)			1 (7.1)			1 (7.1)		
Secondary school	71 (86.6)			8 (9.9)			12 (14.6)			10 (12.3)		
Pre-university	21 (91.3)			9 (39.1)			2 (8.7)			4 (17.4)		
Diploma / Degree	258 (92.8)			60 (21.6)			11 (4.0)			48 (17.3)		
Living areas/regions		17.493	0.002		20.225	<0.001		10.786	0.029		8.670	0.070
Metropolitan cities	177 (94.1)			53 (28.2)			19 (10.1)			26 (13.8)		
Small cities	135 (91.2)			16 (10.8)			3 (2.0)			31 (20.9)		
Rural areas	47 (77.0)			8 (13.1)			4 (6.6)			6 (10.0)		

## DISCUSSION

The results of the current study revealed that most (244 out of 398, 61.3%) respondents had good knowledge about clinical trials, which was somewhat higher than those of the previous studies. A study in Jordan concluded that only 21.8% of survey respondents understood what are clinical trials (12). Al-Lawati et al. who conducted a study in Oman also reported a contrast result in which only 31.3% of participants knew what the term "clinical trials" meant (13). Not only that, another study by Abouelkheir et al. found that most of the northern Saudi general population had either low (57.1%) or moderate (29.6%) overall knowledge scores of clinical trials (14). This finding was surprising, given the relatively low participation rate in clinical trials in Malaysia. It was probably that the better knowledge of Malaysians about clinical trials was due to the education through the "I AM AWARE" campaign conducted by Clinical Research Malaysia. A series of "I AM AWARE" roadshows are held annually across the nation to drive awareness of clinical trials. Through this campaign, misconceptions about clinical trials can be addressed and the public may understand the risks and benefits of participating in one, hence being able to better make informed decisions.

Besides, the results clearly showed a high awareness of clinical trials, with a significant difference according to age, education level, employment status and living areas. 88.7% (353 out of 398) of our sample was aware of clinical trials, which was similar to that reported by Chu et al. in Japan revealing that 75.1% of respondents had heard about clinical trials (11). In our survey, respondents aged 18 - 29 years were more aware of clinical trials. It was probable that the lower awareness in elder age groups was due to digital illiteracy which

hinders their access to clinical trial information. Poorer education could also be the reason why older people had the least awareness about clinical trials. Moreover, there was a significant correlation between higher education level and increasing awareness of clinical trials. This was consistent with the findings of a research conducted in the USA which came to the conclusion that low education levels were predictors of lack of awareness of clinical trials and were linked to lower participation rates (15). Furthermore, citizens of metropolitan cities and small cities were more aware of clinical trials than those in rural areas. This result was different from that of an earlier research conducted in the United States among cancer patients, which reported that inner-city and rural participants had similar levels of awareness about clinical trials (16). However, our findings agreed with those of another study. Kim et al. concluded that in South Carolina, rural residents had a lack of awareness about clinical trials as compared to urban residents (17). Our findings revealed that the majority were more preferred to be allocated for conventional drugs instead of unlicensed drugs or randomly assigned in a clinical trial. People may be reluctant to take part in randomised clinical trials due to the fear of side effects of the drug or treatment. Previous research had covered the issue of patient preference in clinical trials. Agoritsas et al. revealed that random allocation to study arms was linked to a reduced rate of participation (18). Similar findings were found in another study conducted by Creel et al., in which most of the osteoarthritis patients (65%) strongly preferred the type of treatment for their knee problem and were less inclined to take part in a randomized trial (19). Recruitment remained challenging because of the participants' worry about being assigned to the study arm that would be less effective. Our study found that two main reasons why people refused to participate in

clinical trials were concern about drug side effects and fear of the unknown (20).

About 46.5% (185 out of 398) of participants cited recommendations from doctors as their primary motivation for taking part in a clinical trial. This was followed by the potential for own benefit (182 out of 398, 45.7%). These responses are in line with other studies. According to research by Eggly et al., 85% of cancer patients agreed to participate in the clinical trial after getting recommendations from their oncologists. This finding indicates a significant association between oncologists' recommendations and patients' willingness to participate (21). Moreover, Moorcraft et al. pointed out that potential personal benefit was the main motivation for trial participation (22). Another Irish study also showed that the major factor affecting patients' enrolment in trials was associated with personal gain through participation (23).

The willingness to participate in clinical trials was also significantly influenced by the access of information on clinical trials in the current study. This result is consistent with previous reports. According to Comis et al., individuals with a high degree of comprehension of clinical trials were more likely than those with lower levels of understanding to have a favourable attitude towards participation (24). These findings demonstrated that the recruitment and retention of trial participants requires a thorough understanding of clinical trials. Most of the respondents in the present study (315 out of 398, 79.2%) had a general idea about clinical trials from the mass media such as the Internet and TV. Therefore, mass media campaigns could be a good strategy to increase the awareness and participation rate of clinical trials, which was also suggested by previous researchers (25).

We found that younger persons in Malaysia were significantly more likely to believe that clinical trials are necessary as compared to the elderly. This outcome was consistent with a previous study on American cancer patients, which found that younger patients were more possibly than older patients to have a positive perspective on participation in clinical trials (24). Nevertheless, this result was different from that of a study by the Center for Information and Study on Clinical Research Participation (CISCRP) which conducted an online international survey, showed that older individuals valued clinical research more than younger ones did (26). Chu et al. also revealed that younger adults in Korea had a more negative perception of the necessity of clinical trials (11). The majority of participants in the present study were still uncertain about the safety of clinical trials. This was in line with research conducted by Quinn et al. in the United States, which found that 83.3% of cancer patients had the same opinion, mentioning the fear of unknown and the fear of not experiencing a positive health outcome because of the trial (20). Concerns about side effects was cited as the top reasons for viewing clinical

trial as unsafe in the 2017 Perceptions & Insights Study Report by CISCRP (26). A strong association between education level and perception towards the safety of clinical trials was found in this study. Participants with low education levels were more probable to perceive clinical trials as unsafe. As highlighted by other studies, this result indicated the need for education regarding safety monitoring to enhance the chance of future clinical trial participation (27).

The perception towards the confidentiality of clinical trials was not different by gender, education level or living areas in this study. However, those who were older adults had lesser trust in the confidentiality of clinical trials than younger people. It was probably that the lack of confidence in researchers among the elderly was due to their life experiences. Earlier research demonstrated that a previous negative experience or mistrust when obtaining informed consent or building a rapport with their doctors was a deterrent to taking part in clinical trials (28). For instance, a pilot study in the Middle East revealed there was a lack of confidence in doctors, with many participants assuming that doctors may conduct studies without their consent and that leaving a study would result in lower-quality medical treatment being provided (29). Therefore, effective communication between participants and researchers is crucial to establish trust and facilitate clinical trial participation.

Over the last few years, the COVID-19 pandemic might have contributed significant impacts on research and recruitment to trials. A study conducted by CISCRP through an online international survey in 2021 reported that most respondents feel the pandemic has made them more aware of clinical research studies and more willing to take part in clinical trials (30). However, another study conducted through face-to-face interviews in the outpatient department in the United States demonstrated a negative influence of the COVID-19 pandemic on perceptions towards trial involvement. For instance, some participants expressed fear that trials may have inadequate precautionary measures and expressed the need to minimise exposure to the hospital environment in order to minimize the risk for the COVID-19 (31). Accordingly, this COVID-19 pandemic might have an impact on the results obtained in this study.

A major limitation of the study is the sample of convenience and bias towards literate and computer-literate people who are able to access an online survey. The skews of the sample to young, educated and computer literate and the results are therefore not generalisable to the larger population of the country. This may be reflected in the results demonstrating high knowledge of clinical trials. Besides, the samples collected in this study may not be large enough to adequately represent the national population. Despite the limited sample size, the results might be utilized to improve the questionnaire and to conduct larger-scale

research on the subject. Furthermore, willingness to participate in clinical trials only reflects a behavioural intention but not actual enrolment. Due to their propensity to behave in a nice manner, respondents may be more inclined to answer favourably regarding their willingness to participate. Future research should look at the degree to which behavioural intention predicts actual enrolment clinical trials enrolment as well as the conditions under which the participation rate is low.

## CONCLUSION

Our study results show the present level of general public on knowledge, attitudes and perception towards clinical trial participation in Malaysia. These outcomes also shed light on the vital factors that may influence a person's willingness to participate in clinical trials. The findings indicate that the Malaysians had a high level of knowledge and awareness about clinical trials and were willing to participate, especially in case of need. Recommendations from doctors, potential for own benefit and access to more information were the top three influential factors for participating in clinical trials. It is conceivable that recruitment would increase with a better grasp of the viewpoints of the general public who are potential participants in future clinical trials. These findings could help clinical researchers establish a more thorough understanding of the participants and develop effective outreach strategies for clinical trial recruitment and retention.

## ACKNOWLEDGEMENT

This research is supported by the Faculty of Pharmacy, AIMST University.

## REFERENCES

- World Health Organization. International Clinical Trials Registry Platform (ICTRP) [Internet]. [cited 2023 Mar 29]. Available from: <https://www.who.int/clinical-trials-registry-platform>
- Majumder K. A Young Researcher's Guide to A Clinical Trial. Editage Insights [Internet]. 2015 Jul 24 [cited 2023 Mar 29]; Available from: <https://www.editage.com/insights/a-young-researchers-guide-to-a-clinical-trial>
- Center for Information & Study on Clinical Research Participation (CISCRP). The importance of clinical research in underserved communities [Internet]. [cited 2023 Mar 26]. Available from: <https://www.ciscrp.org/the-importance-of-clinical-research-in-underserved-communities/>
- US Food & Drug Administration. 2015-2019 Drug trials snapshots summary report. 2020 Nov.
- US Food & Drug Administration. 2015-2016 global participation in clinical trials report. 2017 Jul.
- Haywood C, Lanzkron S, Diener-West M, Haythornthwaite J, Strouse J, Bediako S, et al. Attitudes Towards Clinical Trials Among Patients with Sickle Cell Disease. *Clin Trials*. 2014 Jun;11(3):275–83. doi: 10.1177/1740774513519876
- Ayodele O, Akhtar M, Konenko A, Keegan N, Calacsan F, Duggan L, et al. Comparing attitudes of younger and older patients towards cancer clinical trials. *J Geriatr Oncol*. 2016 May;7(3):162–8. doi: 10.1016/j.jgo.2016.03.005
- Thornton LR, Amorrortu RP, Smith DW, Mainous AG, Vernon SW, Tilley BC. Exploring Willingness of Elder Chinese in Houston to Participate in Clinical Research. *Contemp Clin Trials Commun*. 2016 Dec 15;4:33–8. doi: 10.1016/j.conctc.2016.06.006.
- Pariera KL, Murphy ST, Meng J, McLaughlin ML. Exploring Willingness to Participate in Clinical Trials by Ethnicity [published correction appears in *J Racial Ethn Health Disparities*. 2016 Oct 31;:]. *J Racial Ethn Health Disparities*. 2017;4(4):763-769. doi:10.1007/s40615-016-0280-6
- Brubaker L, Richter HE, Barber MD, Hsu Y, Rahn DD, Menefee S, et al. Pelvic floor disorders clinical trials: participant recruitment and retention. *Int Urogynecol J*. 2013 Jan;24(1):73–9. doi: 10.1007/s00192-012-1824-x.
- Chu SH, Kim EJ, Jeong SH, Park GL. Factors associated with willingness to participate in clinical trials: a nationwide survey study. *BMC Public Health*. 2015;15:10. doi: 10.1186/s12889-014-1339-0.
- Ahram M, Farkouh A, Haddad M, Kalaji Z, Yanis A. Knowledge of, attitudes to and participation in clinical trials in Jordan: a population-based survey. *East Mediterr Health J*. 2020 May 21;26(5):539–46. doi: 10.26719/2020.26.5.539
- Al-Lawati H, Al-Baimani K, Al-Zadjali M, Al-Obaidani N, Al-Kiyumi Z, Al-Khabori MK. Knowledge and attitudes towards clinical trial participation in Oman: a cross-sectional study. *Sultan Qaboos Univ Med J*. 2018 Feb;18(1):e54–60. doi: 10.18295/squmj.2018.18.01.009
- Abouelkheir M, Taha AE, Thirunavukkarasu A, Alkhamsan WSS, Almutairi FKS, Alanazi AAA, et al. Knowledge and Attitude towards Clinical Trials among General Population of Northern Saudi Arabia during COVID-19 Era: A Cross-Sectional Study. *Healthcare*. 2023 Jan;11(5):680. doi: 10.3390/healthcare11050680
- Brown M, Moyer A. Predictors of awareness of clinical trials and feelings about the use of medical information for research in a nationally representative US sample. *Ethn Health*. 2010 Jun;15(3):223–36. doi: 10.1080/13557851003624281.
- Geana M, Erba J, Krebill H, Doolittle G, Madhusudhana S, Qasem A, et al. Searching for cures: Inner-city and rural patients' awareness and perceptions of cancer clinical trials. *Contemp Clin Trials Commun*. 2016 Dec 18;5:72–9. doi: 10.1016/j.conctc.2016.12.004.
- Kim SH, Tanner A, Friedman DB, Foster C,

- Bergeron CD. Barriers to clinical trial participation: a comparison of rural and urban communities in South Carolina. *J Community Health*. 2014 Jun;39(3):562–71. doi: 10.1007/s10900-013-9798-2.
18. Agoritsas T, Deom M, Perneger TV. Study design attributes influenced patients' willingness to participate in clinical research: a randomized vignette-based study. *J Clin Epidemiol*. 2011 Jan;64(1):107–15. doi: 10.1016/j.jclinepi.2010.02.007.
  19. Creel AH, Losina E, Mandl LA, Marx RJ, Mahomed NN, Martin SD, et al. An assessment of willingness to participate in a randomized trial of arthroscopic knee surgery in patients with osteoarthritis. *Contemp Clin Trials*. 2005 Apr;26(2):169–78. doi: 10.1016/j.cct.2004.12.010.
  20. Quinn GP, Koskan A, Wells KJ, Gonzalez LE, Meade CD, Pozo CLP, et al. Cancer patients' fears related to clinical trial participation: a qualitative study. *J Cancer Educ*. 2012 Jun 1;27(2):257–62. doi: 10.1007/s13187-012-0310-y.
  21. Eggly S, Albrecht TL, Harper FWK, Foster T, Franks MM, Ruckdeschel JC. Oncologists' recommendations of clinical trial participation to patients. *Patient Educ Couns*. 2008 Jan;70(1):143–8. doi: 10.1016/j.pec.2007.09.019.
  22. Moorcraft SY, Marriott C, Peckitt C, Cunningham D, Chau I, Starling N, et al. Patients' willingness to participate in clinical trials and their views on aspects of cancer research: results of a prospective patient survey. *Trials*. 2016 Jan 9;17:17. doi: 10.1186/s13063-015-1105-3.
  23. Walsh E, Sheridan A. Factors affecting patient participation in clinical trials in Ireland: A narrative review. *Contemp Clin Trials Commun*. 2016 Mar 2;3:23–31. doi: 10.1016/j.conctc.2016.01.002.
  24. Comis RL, Miller JD, Aldigñ CR, Krebs L, Stoval E. Public attitudes toward participation in cancer clinical trials. *J Clin Oncol*. 2003 Mar 1;21(5):830–5. doi: 10.1200/JCO.2003.02.105.
  25. Kim JW, Kim SJ, Chung YH, Kwon JH, Lee HJ, Chung YJ, et al. Cancer patients' awareness of clinical trials, perceptions on the benefit and willingness to participate: Korean perspectives. *Br J Cancer*. 2008 Nov 4;99(10):1593–9. doi: 10.1038/sj.bjc.6604750.
  26. 2017 CISCRP perceptions and insights study perceptions and knowledge [Internet]. [cited 2023 Mar 29]. Available from: <https://www.ciscrp.org/wp-content/uploads/2019/06/2017-CISCRP-Perceptions-and-Insights-Study-Perceptions-and-Knowledge.pdf>
  27. Kern-Goldberger A, Hill-Ricciuti AC, Zhou JJ, Savant AP, Rugg L, Dozor AJ, et al. Perceptions of safety monitoring in CF clinical studies and potential impact on future study participation. *Journal of Cystic Fibrosis*. 2019 Jul 1;18(4):530–5. doi: 10.1016/j.jcf.2019.05.001.
  28. Hussain-Gambles M, Atkin K, Leese B. South Asian participation in clinical trials: the views of lay people and health professionals. *Health Policy*. 2006 Jul;77(2):149–65. doi: 10.1016/j.healthpol.2005.07.022.
  29. Hifnawy T, Kobrosly S, Edwards H, Anwar M, Zahran D, Silverman H. Patients' attitudes and perceptions regarding research and their rights: a pilot survey study from the Middle East. *East Mediterr Health J*. 2017 Aug 27;23(7):461–8. doi: 10.26719/2017.23.7.461.
  30. Center for Information & Study on Clinical Research Participation. [cited 2023 Sep 5]. Perceptions and Insights Study. Available from: <https://www.ciscrp.org/services/research-services/perceptions-and-insights-study/>
  31. Abdulhussein D, Yap TE, Manzar H, Miodragovic S, Cordeiro F. Factors impacting participation in research during the COVID-19 pandemic: results from a survey of patients in the ophthalmology outpatient department. *Trials*. 2022 Sep 30;23(1):823. doi: 10.1186/s13063-022-06748-1.