

Malaysian Patient Perspectives on Clinical Trial Participation: Willingness, Knowledge, Perceptions, Confidence, and Religious Barriers

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Abstract

Despite the expanding landscape of clinical trials, there is a lack of study concerning Malaysian patients' participation and perspectives. This study addresses these gaps by assessing patients' willingness, knowledge, perceptions, confidence, and religious barriers related to clinical trial participations in a clinical trial hospital in Malaysia. We conducted a cross-sectional survey at Sarawak General Hospital from March to September 2022, encompassing 763 cancer and non-cancer patients. We collected patients' responses and calculated scores for domains such as willingness to participate (40.5/100), clinical trial knowledge (29.9/100), perceived benefits (66.5/100) and risks (72.4/100) of participations, confidence in clinical trial conducts (66.3/100), and religious barriers (49.8/100). Cancer patient demonstrated significantly greater willingness for trials involving new drugs (scores: 31.9/100 vs 27.4/100, $p = 0.021$) but slightly higher religious barriers compared to non-cancer cohort (scores: 51.4/100 vs 48.3/100, $p = 0.006$). Multivariable logistic regression identified female gender, unemployment, poor knowledge, low perceived benefits, high perceived risks, and low confidence as significant factors negatively associated with willingness to participate in clinical trials ($p < 0.05$). This study underscores the challenges in engaging Malaysian patients in clinical trials, emphasising the need for targeted strategies to raise awareness, effective communication on benefits and risks, and enhancing public confidence to promote clinical trial participation.

1. Introduction

Participant recruitment rate is a major barrier to clinical trial completion. A study showed that only one-third of the approved trials met their original recruitment goals, and half of the trials had to be extended [1]. Inadequate recruitment can result in an underpowered trial, which increases the risk of prematurely abandoning a potentially effective treatment before its actual clinical effect has been determined. Consequently, participants may be exposed to the uncertain effects of a trial intervention, but the true effect of the trial intervention cannot be determined and raises ethical concerns [2].

In Malaysia, Clinical Research Malaysia reported that there were more than 1800 industry-sponsored research conducted in the Ministry of Health (MOH) facilities from 2012 to 2021 [3]. Malaysia has a large, multi-ethnic population, which provides inherent advantages in terms of genetic diversity for clinical trials. In recent years, the Malaysian government has made efforts to expand the capacity for clinical research. The availability of medical experts and qualified investigators, as well as ethical review and regulatory frameworks for clinical research, all contribute to the growth of Malaysia's clinical trial industry [3–5].

Although there is a growing need for, and an increasing number of clinical trials, there is a lack of study on clinical trial participation and patients' perspectives in Malaysia. Sarawak General Hospital (SGH) as the largest hospital in Sarawak region, Malaysia, serves a catchment area of 2.5 millions people. It is also one of the primary clinical trial centres and the first accredited first-in-human trial site in Malaysia [4]. In this study, we conducted a survey with patients visiting SGH to evaluate their perspectives on clinical trial

participation. We assessed their willingness to participate in clinical trials, knowledge, perceived benefits and risks of participations, confidence in clinical trial conducts, and religious barriers that may hinder their participations. We also determined the factors associated with their willingness to participate in clinical trials

2. Methods

This study was conducted between March 18 and September 20, 2022. We collected responses from adult patients visiting oncology, neurology, respiratory, and endocrinology clinics in SGH during the study period. We excluded individuals who were under the age of 18, those who were illiterate or unable to understand the questionnaire in English, Malay, or Chinese, and those who were mentally incapable to answer the questionnaire. The study protocol was approved by the Medical Research and Ethics Committee of the Ministry of Health of Malaysia (NMRR ID-22-00180-FCT) and was conducted in compliance with the Malaysian Guideline for Good Clinical Practice and Declaration of Helsinki. The participants provided their informed consent prior to participating in the study.

We developed and validated a questionnaire called JoinCT Questionnaire to primarily assess patients' willingness to participate in clinical trials, knowledge about clinical trials, perceived benefits and risks of participation, and confidence in the conducts of clinical trial. Questions for religious barriers were included as additional items in the current study. The JoinCT Questionnaire is available in three languages: English, Bahasa Malaysia, and Chinese. Details of the development and validation process of the JoinCT Questionnaire were published elsewhere [6].

In this study, we collected respondents' socio-demographic information, cancer status, prior exposure to clinical trials, and participation history. In addition, the respondents would rate their current health status and their relationship with their healthcare providers on a 10-point numeric scale.

In the questionnaire, the participants would rate their willingness to participate in a clinical trial in five scenarios: clinical trials involving a new, unmarketed drug, new indication for marketed drugs, new medical device, new medical procedure, or general clinical trials, on a 10-point numeric scale. We multiplied the score for willingness in each clinical trial scenario by a factor of 10 and then computed the average of these sub-scores across the five scenarios to determine the overall willingness score.

The participants' knowledge of clinical trials was evaluated with eight questions; each correct answer would be awarded one point and each incorrect or uncertain response would be awarded zero point. In addition, they would provide their responses about their perceptions of benefits and risks of participating in clinical trials, their confidence in the conduct of clinical trials, and religious barriers, on a 5-point Likert scale ranging from 'strongly disagree' to 'strongly agree'. We converted the Likert scale responses into numerical values, with 'strongly disagree' to 'strongly agree' being assigned one to five points, respectively. To calculate the scores, we summed the points obtained in each domain, divided the total by the maximum points, and multiplied the result by 100.

Categorical variables, such as gender and other demographics, were reported as frequencies and percentages. Continuous variables, such as scores, age, self-rated health status, and relationship with healthcare providers ratings were reported as means and standard deviations. We used independent t-test to compare the scores between cancer and non-cancer patients. Logistic regression analysis was conducted to determine the factors associated with a high willingness ($\geq 70/100$) to participate in clinical trials. The significant variables from the univariable analysis were included in two multivariable models. Model 1 comprised the significant socio-demographic factors and clinical trial knowledge score. Model 2 included all the variables from Model 1, along with the scores for perceived benefits, perceived risks, confidence in clinical trial, and religious barriers to clinical trial participation. A p-value of less than 0.05 was considered statistically significant.

3. Results

A total of 763 patients responded to the questionnaire and were included for analysis. The mean age was 51.5 (standard deviation 15.4) years and approximately one-third were female. The majority were Chinese (37.6%) and Malay (30.4%) ethnicity. More than 98% of the respondents claimed to have a religion, with Christians (42.6%) and Muslims (34.2%) being the two largest religious groups. Most of them had received secondary or higher education (80.2%) and were unemployed (53.9%), with 64.6% earning less than RM1200 (~USD270) per month (Table 1).

Among the respondents, 51.2% had cancer and were from the oncology clinic and the rest were from the neurology (16.8%), endocrinology (16.6%), and respiratory (15.3%) clinics. The majority of the cancer patients had breast cancer (34.9%), followed by colorectal (12.3%), lung (11.3%), and nasopharyngeal (9.5%) cancers; over one-third of them were in stage IV (Supplementary materials, Table S1).

Approximately 40% of respondents had prior exposure to clinical trials, with most learning about clinical trials through doctors (11.1%), social media (9.2%), or family and friends (9.0%). Additionally, only 8.1% had participated in a trial before. Respondents rated their health at a mean value of 6.6/10 and their relationship with healthcare providers at a mean value of 8.2/10 (Table 1).

The respondents showed a moderate-to-low willingness to participate in clinical trials with a mean score of 40.5/100. Among the respondents, only 13% expressed a high willingness score ($\geq 70/100$). They were least willing to participate in trials involving new, unmarketed drugs (29.7/100), but most willing for trials involving medical devices (44.5/100) (Table 2).

Our study respondents showed poor clinical trial knowledge, with a mean score of only 29.9/100 (Table 3). In the post-hoc analyses, significant differences of knowledge score were found across various socio-demographic factors such as ethnicity, religion, education level, employment status, and income (Table S1).

Table 4 presents our patients' perceptions, confidence in clinical trials, and religious barriers hindering their clinical trial participation. The scores for perceived benefits and perceived risks of clinical trial

participations are 66.5/100 and 72.4/100, respectively. It is worth mentioning that the statement on receiving monetary benefits is an advantage, received the lowest proportion of agreement, with only about 30% of participants agreeing to it. Besides that, only 28.4% of them agreed that the benefits of participating in clinical trials outweighed the associated risks. In contrast, the majority of patients (60–70%) acknowledged potential risks related to clinical trial participation, including concerns about safety, perceived ineffectiveness, discomforts, giving up certain rights, and the burden of participation. (Table 4).

The score for confidence in clinical trial conducts is 66.3/100. However, less than half of the respondents (40-45%) agreed with the statements in regarding their confidence in clinical trials conducts, including ethical standards and qualification of investigators, safety of participation, and patient's rights and privacy in trials. (Table 4). In terms of religious barriers, the score is 49.8/100. Only about 10-11% of the respondents cited religious teachings or beliefs, religious duty or spiritual practices, and disapproval from religious leaders and/or members as barriers to their participation in clinical trials.

When comparing cancer patients to non-cancer patients, both groups showed comparable levels of overall willingness to participate in clinical trials (41.2/100 vs. 39.8/100, $p=0.434$); however, cancer patients were slightly more inclined to participate in trials involving novel drugs (31.9/100 vs. 27.4/100, $p=0.021$). No significant differences were found in other clinical trial scenarios. Although cancer patients showed marginally higher scores concerning religious barriers (51.4/100 vs 48.3/100, $p=0.006$), there are no significant differences in their scores for knowledge, perceived benefits and risks, or confidence in the conduct of clinical trials (Table 5)

In logistic regression analysis, Model 1 shows that being male [OR 1.75 95%CI (1.11, 2.75)] and having a higher knowledge score [OR 1.01 95%CI (1.01, 1.02)] are significantly associated with the high willingness to participate in clinical trials, whereas unemployment has negative association [OR 0.40 95%CI (0.18, 0.89)], In Model 2, being employed [OR 2.68 95%CI (1.05, 6.84)], having a higher perceived benefit score [OR 1.10 95%CI (1.06, 1.13)], a lower perceived risk score [OR 0.95 95%CI (0.93, 0.96)], and a higher score for confidence in clinical trial conducts [OR 1.03 95%CI (1.00, 1.05)] are the significant factors associated with a high willingness score to participate in clinical trials (Table 6). The univariable analysis results are supplied in the supplementary table (Supplementary materials, Table S2).

4. Discussion

Overall, our patients showed a moderate-to-low willingness to participate in clinical trials. Clinical trials involving new drugs received the lowest willingness rating to participate. This could be related with their concerns towards the safety and efficacy of new drugs, which could be seen from their responses on their perceived benefit and risks of clinical trials in this study. Studies showed that perception towards unproven treatment and fear of its side effects were among the main reasons why individuals declines to participate in clinical trial [7, 8]. However, we found that cancer patients were more willing to participate in trials involving new drugs compare to non-cancer patients, possibly due to their greater need for alternative treatments.

Consistent with previous studies, our respondents' concerns revolved around the safety and inefficacy of the treatment [9–11]. We found that higher perceived benefits and lower perceived risks were associated with high willingness to participate in clinical trial trials. Effective communication about the potential benefits and risks of clinical trial participation and addressing patients' concerns is therefore crucial [12]. Researchers or healthcare providers need to provide the patients with clear information and education about the clinical trials, as well as offer support and reassurance throughout the study process.

Only about 40% of our respondents had heard of clinical trial before the survey. In addition, the majority had poor knowledge about clinical trials, but those with better knowledge about clinical trials were more willing to participate, which is consistent with previous studies [8, 13]. We also found significant disparities in clinical trial knowledge among patients from different socio-economic backgrounds in *post hoc* analysis (Supplementary materials, Table S3). There is a need for more targeted efforts, including public campaigns, community education programs, and other outreach initiatives, which are tailored to different communities to improve the public awareness and knowledge about clinical trials [14, 15]. Besides, that social media can be leveraged as an effective tool for disseminating clinical trial information and boosting recruitment [16, 17]. Nonetheless, caution is warranted as the use of social medial may pose challenges for the privacy, confidentiality, and integrity of clinical trials [18].

We also need to address the lack of confidence in the clinical trial processes and investigator's roles among our patients. Building trust with the clinical team and ensuring ethical trial conduct is critical. Research indicates that patients' distrust towards medical researchers hinders their participation in clinical trials [19, 20]. Misinformation from the internet and social media may also undermine confidence and attitudes towards trials [21, 22]. It is essential, therefore, to improve transparency in research and enhance communication regarding trial process and results with the public. Moreover, we suggest to enhance the visibility of Malaysia's clinical trial regulatory framework to reinforce public confidence in trial integrity. The entails highlighting the Medical Research and Ethics Committee's oversights on research involving the MOH facilities, patients, and investigators, as well as other independent review boards across universities and non-MOH hospitals, alongside the National Pharmaceutical Regulatory Authority's roles in ensuring trials' compliance with regulations, ethical standards, and guidelines in this country [23].

In terms of demographic factors, our study revealed a significant disparity in the willingness to participate in clinical trials between female and male patients. Studies showed that women tend to be more risk-averse, [24, 25] which may be a contributing factor why the female patients are less willing to participate in a perceived high-risk activity such as clinical trials [26]. A further study is warranted to assess barriers to recruitment and inclusion of women in clinical trials in Malaysia.

Besides that, compared to employed patients, unemployed individuals showed a significantly lower willingness to participate in clinical trials. We postulate this could be attributed to their sensitivity to the costs of participating due to poorer income and financial insecurities. However, we did not find personal income to be a significant factors associated with willingness to participate in clinical trials in this study.

On the other hand, our study showed that monetary compensation was not a significant driver for clinical trial participation among our patients. Only 30% of our respondents agreed that it is a benefit of participating in a trial. This was in contrast to a study from Indonesia that found increased willingness with higher financial compensation [27]. Nonetheless, we believe this could also be due to the poor understanding of clinical trials and the respondents might not be aware of possible monetary compensation for participating in a clinical trial.

Even though almost all our respondents reported having a religious affiliation, only a small fraction (10–11%) agreed that their religious beliefs, obligations, peers and leaders affected their decision to participate in clinical trials. This showed that religious practice and the religious community support may not play a significant role in affecting clinical trial participation in our community. This is in contrast with a study by Daverio-Zanetti *et al.*, which found that higher religiosity was associated with a perceived lack of community support for clinical trial participation among Hispanic Americans [28]. Nevertheless, as we did not assess the religiosity of our patients in the present study and our findings may be specific to the local context, further research is needed.

Our study had several limitations. Firstly, it was a single-centred study conducted at SGH. However, SGH as the main tertiary referral centre in Sarawak region serves a large patient population. For instance, SGH is the only public oncology centre, providing care for the majority of cancer patients in Sarawak. Therefore, our study has a good representation of the patient population in Sarawak. Nevertheless, a larger national study is warranted to investigate clinical trial participation in the national population. Secondly, there was a possibility of sampling bias as we only approached patients who were able to answer the survey at the clinics. Illiterate, low-educated patients might have been underrepresented. Thirdly, the study was conducted in a hospital setting, which might have influenced the responses of the patients. They might feel pressured to respond quickly while waiting for their clinic appointments. However, we addressed this issue by ensuring anonymity in answering the questionnaire and allowing participants to submit their responses at a later time or on their next visit to the hospital.

In summary, our study highlighted the challenges in engaging Malaysian patients in clinical trials, with the factors such as poor knowledge, low perceived benefits, high perceived risks, and poor confidence in clinical trial conducts contributing to the overall lack of willingness to participate. Our findings suggest the need for targeted efforts to raise awareness and understanding, provide clear and balanced information on benefits and risks, and enhance the public's confidence in the clinical trial process and investigator' roles. The insights from the present study would be useful to understand the drivers and barriers to clinical trial participation, as well as for formulating strategies to promote such participations and patient inclusion in clinical trials in Malaysia.

Declarations

Data Availability Statement

The datasets generated during and/or analysed during the current study are available from the corresponding author on reasonable request.

Author Contributions

TLK, SHT, SSNT, WHL, MAB, and PJV developed the questionnaire and designed the study protocol. TLK and SHT collected the data. TLK, SHT, and MAB analysed the data. TLK conceived the manuscript. All authors interpreted the findings and approved the final manuscript.

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Additional Information

Conflicting Interests

The authors declare that there is no conflict of interest.

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References

1. McDonald, A. M. *et al.* What influences recruitment to randomised controlled trials? A review of trials funded by two UK funding agencies. *Trials* 7, 9 (2006). <https://doi.org:10.1186/1745-6215-7-9>
2. Treweek, S. *et al.* Strategies to improve recruitment to randomised controlled trials. *Cochrane Database Syst Rev*, MR000013 (2010). <https://doi.org:10.1002/14651858.MR000013.pub5>
3. Phase 1 Realisation Project Report (P1RP) 2016–2021, https://clinicalresearch.my/wp-content/uploads/2022/03/P1RP-report-REVISED_16-Mar__compressed.pdf (2022).
4. Voon, P. J. *et al.* Early phase oncology clinical trials in Malaysia: current status and future perspectives. *Asia Pac J Clin Oncol* (2022). <https://doi.org:10.1111/ajco.13886>
5. Khalid, K. F. & Ooi, A. J. A. Malaysia's Clinical Research Ecosystem, <https://www.appliedclinicaltrials.com/view/malaysia-s-clinical-research-ecosystem> (2017).
6. Tan, S. H. *et al.* Development and validation of Join Clinical Trial Questionnaire (JoinCT). *Asia Pac J Clin Oncol* (2023). <https://doi.org:10.1111/ajco.14034>
7. Lim, Y. *et al.* Korean Cancer Patients' Awareness of Clinical Trials, Perceptions on the Benefit and Willingness to Participate. *Cancer Res Treat* 49, 1033–1043 (2017). <https://doi.org:10.4143/crt.2016.413>

8. Ellis, P. M., Butow, P. N., Tattersall, M. H., Dunn, S. M. & Houssami, N. Randomized clinical trials in oncology: understanding and attitudes predict willingness to participate. *J Clin Oncol* 19, 3554–3561 (2001). <https://doi.org:10.1200/JCO.2001.19.15.3554>
9. Quinn, G. P. *et al.* Cancer patients' fears related to clinical trial participation: a qualitative study. *J Cancer Educ* 27, 257–262 (2012). <https://doi.org:10.1007/s13187-012-0310-y>
10. Manne, S. *et al.* Attitudinal barriers to participation in oncology clinical trials: factor analysis and correlates of barriers. *Eur J Cancer Care (Engl)* 24, 28–38 (2015). <https://doi.org:10.1111/ecc.12180>
11. Unger, J. M. *et al.* Patient income level and cancer clinical trial participation. *J Clin Oncol* 31, 536–542 (2013). <https://doi.org:10.1200/JCO.2012.45.4553>
12. Walsh, E. & Sheridan, A. Factors affecting patient participation in clinical trials in Ireland: A narrative review. *Contemporary Clinical Trials Communications* 3, 23–31 (2016). <https://doi.org:10.1016/j.conctc.2016.01.002>
13. Mosconi, P. *et al.* Knowledge and attitudes towards clinical trials among women with ovarian cancer: results of the ACTO study. *Journal of Ovarian Research* 15 (2022). <https://doi.org:10.1186/s13048-022-00970-w>
14. Heller, C. *et al.* Strategies addressing barriers to clinical trial enrollment of underrepresented populations: A systematic review. *Contemporary Clinical Trials* 39, 169–182 (2014). <https://doi.org:10.1016/j.cct.2014.08.004>
15. Michaels, M. *et al.* “The Promise of Community-Based Advocacy and Education Efforts for Increasing Cancer Clinical Trials Accrual”. *Journal of Cancer Education* 27, 67–74 (2011). <https://doi.org:10.1007/s13187-011-0271-6>
16. Geist, R. *et al.* Social Media and Clinical Research in Dermatology. *Current Dermatology Reports* 10, 105–111 (2021). <https://doi.org:10.1007/s13671-021-00350-5>
17. Sedrak, M. S., Cohen, R. B., Merchant, R. M. & Schapira, M. M. Cancer Communication in the Social Media Age. *JAMA Oncology* 2 (2016). <https://doi.org:10.1001/jamaoncol.2015.5475>
18. Thompson, M. A. & O'Regan, R. M. Social media and clinical trials: The pros and cons gain context when the patient is at the center. *Cancer* 124, 4618–4621 (2018). <https://doi.org:10.1002/cncr.31747>
19. Abdelhafiz, A. S. *et al.* Factors Influencing Participation in COVID-19 Clinical Trials: A Multi-National Study. *Front Med (Lausanne)* 8, 608959 (2021). <https://doi.org:10.3389/fmed.2021.608959>
20. Braunstein, J. B., Sherber, N. S., Schulman, S. P., Ding, E. L. & Powe, N. R. Race, medical researcher distrust, perceived harm, and willingness to participate in cardiovascular prevention trials. *Medicine (Baltimore)* 87, 1–9 (2008). <https://doi.org:10.1097/MD.0b013e3181625d78>
21. Borges do Nascimento, I. J. *et al.* Infodemics and health misinformation: a systematic review of reviews. *Bull World Health Organ* 100, 544–561 (2022). <https://doi.org:10.2471/BLT.21.287654>
22. Islam, M. S. *et al.* COVID-19 vaccine rumors and conspiracy theories: The need for cognitive inoculation against misinformation to improve vaccine adherence. *PLoS One* 16, e0251605 (2021). <https://doi.org:10.1371/journal.pone.0251605>

23. Malaysian Guideline for Good Clinical Practice (GCP) Inspection, <https://www.npra.gov.my/easyarticles/images/users/1059/NPRA-GUIDELINES-FOR-GCP-INPECTION-IN-MSIA-ED2.1.pdf> (2023).
24. Harris, C. R. & Jenkins, M. Gender Differences in Risk Assessment: Why do Women Take Fewer Risks than Men? *Judgment and Decision Making* 1, 48–63 (2006). <https://doi.org/10.1017/S1930297500000346>
25. Pawlowski, B., Atwal, R. & Dunbar, R. I. M. Sex Differences in Everyday Risk-Taking Behavior in Humans. *Evolutionary Psychology* 6, 147470490800600104 (2008). <https://doi.org/10.1177/147470490800600104>
26. Ding, E. L., Powe, N. R., Manson, J. E., Sherber, N. S. & Braunstein, J. B. Sex differences in perceived risks, distrust, and willingness to participate in clinical trials: a randomized study of cardiovascular prevention trials. *Arch Intern Med* 167, 905–912 (2007). <https://doi.org/10.1001/archinte.167.9.905>
27. Harapan, H. *et al.* Willingness to Participate and Associated Factors in a Zika Vaccine Trial in Indonesia: A Cross-Sectional Study. *Viruses* 10 (2018). <https://doi.org/10.3390/v10110648>
28. Daverio-Zanetti, S. *et al.* Is Religiosity Related to Attitudes Toward Clinical Trials Participation? *Journal of Cancer Education* 30, 220–224 (2014). <https://doi.org/10.1007/s13187-014-0696-9>

Tables

Table 1. Background characteristics

Variables		n = 763
Age, years		51.5 ± 15.4
Gender	Male	254 (33.3)
	Female	509 (66.7)
Ethnicity	Chinese	287 (37.6)
	Malay	232 (30.4)
	Iban	121 (15.9)
	Bidayuh	91 (11.9)
	Others	32 (4.2)
Religion	Christianity	325 (42.6)
	Islam	261 (34.2)
	Buddhism	117 (15.3)
	Others	41 (5.4)
	No religion	19 (2.5)
Education	No formal education	52 (6.8)
	Primary	99 (13.0)
	Secondary	389 (51.0)
	Tertiary	223 (29.2)
Marital status	Married	574 (75.2)
	Single	145 (19.0)
	Widowed/divorced	44 (5.8)
Employment status	Unemployed	411 (53.9)
	Employed	250 (32.8)
	Retired	102 (13.4)
Monthly Income	< RM1200	493 (64.6)
	RM1200 – RM2999	131 (17.2)
	RM3000 – RM4999	78 (10.2)
	≥ RM5000	61 (8.0)
Clinical trial exposure	Overall	309 (40.5)

Social media	70 (9.2)
Internet, other than social media	52 (6.8)
Doctors	85 (11.1)
Family members or friends	69 (9.0)
Print media	54 (7.1)
TV or radio	44 (5.8)
Others	7 (0.9)
Prior clinical trial participation	62 (8.1)
Cancer diagnosis	391 (51.2)
Self-rated health status, 1 to 10 scale	6.6 ± 2.0
Self-rated healthcare provider relationship, 1 to 10 scale	8.2 ± 1.8

Data are presented as n (%) for categorical variables or mean ± standard deviation for continuous variables.

Table 2. Willingness to participate in clinical trials between cancer and non-cancer patients.

Willingness to participate	Willingness scores
New and unmarketed drug trials	29.7 ± 27.0
Marketed drug with new indication trials	42.1 ± 28.6
Medical procedure trials	43.8 ± 27.5
Medical device trials	44.5 ± 27.9
General clinical trials	42.4 ± 27.2
Overall	40.5 ± 25.4
Score ≥70%	99 (13.0)

The willingness score and subscores are presented as mean ± standard deviation while the proportion of patients who had ≥70% willingness score is presented as n (%).

Table 3. Clinical trial knowledge responses and score

Clinical Trial Knowledge	Patients who answered correctly, n (%)
Clinical trials are research that test medications, medical devices, or procedures in humans.	255 (33.4)
Some clinical trials are sponsored by private companies (generally drug, medical device, or biotech companies) or government agencies.	181 (23.7)
Before a clinical trial can begin, an Ethics Committee or an Institutional Review Board will review and approve the trial.	208 (27.3)
Clinical trials are usually carried out by a research team led by a specialist known as the Principal Investigator.	222 (29.1)
Before you join a clinical trial, your eligibility will be evaluated according to the requirements of the study.	251 (32.9)
Your doctor can decide on your behalf and enroll you in a clinical trial without your consent if he thinks it benefits you.	238 (31.2)
Before joining a clinical trial, you will be informed of the details of the trial, including the purpose and objective of the trial, the procedures involved, the risks and benefits involved.	268 (35.1)
After you are enrolled in a clinical trial, you can withdraw freely from the trial at any time.	203 (26.6)
Score	29.9 ± 36.8

Score is presented as mean ± standard deviation.

Table 4. Perceived benefits and risks, confidence in clinical trials, and religious barriers responses and scores

Domains	Patients who agreed/strongly agreed, n (%)
Perceived benefits	
Helping my disease/condition.	351 (46.0)
Receiving monetary benefits	225 (29.5)
Doctors and nurses paying more attention and time on me	315 (41.3)
Having a more active role in my health	290 (38.0)
Receiving new treatment or medical procedures that are otherwise not affordable or available	310 (40.6)
Helping my family to understand my condition better.	292 (38.3)
Helping others to get a better treatment in the future.	431 (56.5)
Helping the advancement of healthcare in my community or country.	424 (55.6)
Participating in clinical trials has more benefits than risks.	217 (28.4)
Score	66.5 ± 13.0
Perceived risks	
Concerned about the safety of participating in a clinical trial.	537 (70.4)
Trial treatment may not work	499 (65.4)
Concerned about the discomforts during trial procedures	499 (65.4)
Having to give up rights and be used as a test subject	455 (59.6)
Burdening me and my family	467 (61.2)
Score	72.4 ± 17.6
Confidence in clinical trial conducts	
Participating in clinical trials is safe	229 (30.0)
My rights and privacy will be upheld	279 (36.6)
Researchers have the highest level of ethical standards	308 (40.4)
Receive proper treatment if anything happens	302 (39.6)
Investigators are experts in their fields	341 (44.7)
Score	66.3 (14.4)

Religious barriers	
Clinical trial participation contradicts my religion's teachings/my beliefs.	83 (10.9)
Clinical trial participation affects my religious duty or spiritual practices	85 (11.1)
Disapproval from religious leaders and/or members	75 (9.8)
Score	49.8 ± 15.8

Scores are presented as means ± standard deviations.

Table 5. Score differences between cancer and non-cancer cohorts

Domains	Cancer	Non-cancer	p-value
Willingness to participate	41.2 ± 25.4	39.8 ± 25.4	0.434
New and unmarketed drug trials	31.9 ± 27.6	27.4 ± 26.3	0.021
Marketed drug with new indication trials	44.0 ± 28.3	40.2 ± 28.8	0.068
Medical procedure trials	43.7 ± 27.1	43.9 ± 28.0	0.893
Medical device trials	43.8 ± 27.5	45.2 ± 8.3	0.487
General clinical trials	42.7 ± 26.6	42.1 ± 27.8	0.766
Knowledge	28.9 ± 34.6	31.0 ± 39.0	0.436
Perceived benefits	65.6 ± 13.5	66.7 ± 12.5	0.065
Perceived risks	71.3 ± 17.5	73.4 ± 17.8	0.098
Confidence in clinical trial conducts	66.0 ± 14.5	66.7 ± 14.4	0.482
Religious barriers	51.4 ± 15.5	48.3 ± 16.1	0.006

Scores are presented as means ± standard deviations.

Table 6. Logistic regression analysis of factors associated with high willingness ($\geq 70\%$) to participate in clinical trials

Variables	Univariable			Multivariable					
				Model 1 ^a			Model 2 ^b		
	OR	95% CI	p-value	OR	95% CI	p-value	OR	95% CI	p-value
Gender, Male	1.81	1.18, 2.78	0.006	1.75	1.11, 2.75	0.015	1.61	0.97, 2.70	0.071
Employment status									
Employed	1.00	Ref	Ref	1.00	Ref	Ref	1.00	Ref	Ref
Unemployed	0.57	0.36, 0.90	0.016	0.40	0.18, 0.89	0.026	0.37	0.15, 0.95	0.039
Retired	1.02	0.55, 1.89	0.951	0.63	0.29, 1.38	0.244	0.56	0.23, 1.34	0.193
Monthly Income									
< RM1200	1.00	Ref	Ref	1.00	Ref	Ref	1.00	Ref	Ref
RM1200–RM2999	0.97	0.53, 1.77	0.921	0.43	0.18, 1.01	0.054	0.52	0.19, 1.40	0.195
RM3000–RM4999	1.23	0.62, 2.47	0.557	0.49	0.19, 1.26	0.138	0.45	0.15, 1.33	0.146
≥ RM5000	2.45	1.28, 4.66	0.006	0.75	0.30, 1.89	0.545	0.78	0.27, 2.29	0.650
Prior clinical trial exposure	2.44	1.59, 3.76	<0.001	1.23	0.69, 2.19	0.486	0.89	0.46, 1.72	0.739
Knowledge	1.02	1.01, 1.02	<0.001	1.01	1.01, 1.02	<0.001	1.01	1.00, 1.02	0.069
Perceived benefits	1.11	1.08, 1.14	<0.001	NA	NA	NA	1.10	1.06, 1.13	<0.001
Perceived risks	0.96	0.95, 0.98	<0.001	NA	NA	NA	0.95	0.93, 0.96	<0.001
Confidence in clinical trial conducts	1.07	1.05, 1.09	<0.001	NA	NA	NA	1.03	1.00, 1.05	0.024
Religious barriers	0.98	0.97, 0.99	0.004	NA	NA	NA	0.99	0.98, 1.01	0.368

^a Model 1 includes gender, employment status, monthly income, prior clinical trial exposure, and knowledge score. ^bModel 2 includes all variables in Model 1 and scores for perceived benefit, perceived

risk, confidence in clinical trial conducts, and religious barriers. OR, odd ratio; CI, confidence interval; NA, not applicable, ref, reference.

Supplementary Files

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- [SupplementaryTablesS1S3.docx](#)