

Original Article

Barriers to Clinical Trial Enrollment: KCSG Survey-Based Perspectives of Medical Oncologists, Patients, and Their Caregivers

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Abstract

Purpose

Despite the critical role of clinical trials in advancing cancer treatment, patient enrollment remains challenging in South Korea. We aimed to identify key barriers to clinical trial participation from the perspectives of medical oncologists, patients, and caregivers.

Materials and Methods

Two web-based surveys were conducted in August 2022: one involving 100 KCSG-affiliated medical oncologists, and another involving 100 cancer patients and 100 caregivers. Structured questionnaires were used to assess experiences, perceived barriers, and access to trial-related information. Focus group interviews (FGIs) were conducted with six patients and caregivers to explore qualitative insights in greater depth.

Results

Among oncologists, 98% had prior experience with clinical trials; the same proportion expressed willingness to refer patients to other institutions. However, 76% reported failed or abandoned referral attempts, primarily due to insufficient information on trial eligibility and enrollment status. Although 86% of patients and caregivers were aware of the clinical trial, only 23% had actual participation experience. Physician recommendations emerged as the most influential factor driving participation. Nonetheless, most reported difficulties in accessing reliable trial information, citing unfamiliarity with search tools, complex content, and absence of centralized platforms. The FGI findings supported these results, highlighting the importance of physician guidance and identifying limited access to information as major barriers to enrollment.

Conclusion

Despite positive attitudes, clinical trial participation remains constrained by fragmented referral systems and inaccessible information. Establishing a coordinated, interinstitutional referral platform and improving user-friendly information delivery may enhance enrollment and promote equitable access to cancer clinical trials in South Korea.

Keywords Survey and questionnaires, Neoplasms, Medical oncologists, Patients, Caregivers, Information access

Accepted Article

Introduction

Cancer remains a leading cause of death globally, including South Korea. In 2022, approximately 20 million new cancer cases and 9.7 million deaths were reported worldwide, with projections of 35 million new cases by 2050 [1]. In South Korea, cancer incidence continues to rise annually and remains the leading cause of death, ranking first among all causes of mortality [2,3]. Although the rising incidence of cancer poses a significant global health burden, cancer mortality rates have continuously declined in recent years in certain regions, including Korea and the United States [3,4]. This trend is promising and is largely attributable to improvements in lifestyle, and more notably, advancements in targeted and immunotherapies.

The development of novel therapies has been made possible through clinical trials, which are essential for addressing intractable diseases such as cancer. The successful conduct of clinical trials, particularly multicenter clinical trials, requires close collaboration among institutions, participating investigators, and patients. However, due to resource limitations and patient diversity, not all hospitals can participate in every trial. Therefore, active cooperation among diverse medical institutions is essential for successful and efficient execution of clinical trials. This study aimed to identify barriers to clinical trial enrollment among medical oncologists in South Korea and to examine the perceptions and challenges experienced by patients with cancer and their caregivers regarding trial participation. Ultimately, this research aimed to highlight critical issues and establish a foundation for the future expansion and more efficient implementation of cancer clinical trials.

Materials and Methods

This study was based on survey results exploring the perceptions and challenges faced by medical oncologists in South Korea regarding patient enrollment in clinical trials as

well as the attitudes of potential participants and their caregivers toward trial participation. The survey served as an initial step toward establishing a foundation for investigator-driven multicenter cancer clinical trials promoted by the Korean Cancer Study Group (KCSG) to support nonprofit collaborative research. Separate questionnaires were designed for physicians and patients/caregivers tailored to the characteristics of each group. Participation in the survey was independent of prior involvement in a specific clinical trial. As the survey was conducted exploratively for the aforementioned practical purposes and was not originally intended as a research study, it did not undergo prior review or approval by Institutional Review Board (IRB).

1. Participants

Separate surveys were conducted for healthcare providers and patients/caregivers. A quantitative online survey was conducted between August 16 and 29, 2022, targeting 100 medical oncologists affiliated with the KCSG, all of whom had experience in cancer diagnosis and treatment. For patients and caregivers, a quantitative online survey was conducted with 100 cancer patients and 100 caregivers between August 16 and August 31, 2022. Both surveys were administered using structured questionnaires designed as online web surveys, allowing participants to access via links or QR codes. Additionally, a qualitative study was performed through focus group interviews (FGIs) with six participants consisting of cancer patients and their caregivers. The FGIs were designed to explore participants' perspectives in greater depth and included discussions moderated by a facilitator. The FGIs were conducted virtually, using a videoconferencing platform. All the participants were recruited through voluntary responses to KCSG promotional efforts. A summary of the FGI methodology and key findings is provided in S1 Table.

2. Structure and Content of the Survey

The survey for medical oncologists included 17 items across two main sections, along with a separate background questionnaire that collected demographic and professional information, including work location, primary cancer type, oncology experience, and clinical trial participation as an investigator. The first section addressed the current status and barriers to clinical trial participation, including five questions on methods used to access information and five questions about the challenges encountered in enrolling patients. The second section examines the need for a clinical trial information-sharing platform, with seven questions to assessing oncologists' requirements for accessing trial details across institutions, such as patient eligibility. Some items contained sub-questions to elicit more detailed responses. Similarly, the patient and caregiver surveys were divided into two sections. Section one included 16 questions on perceptions, experiences, and motivations related to cancer clinical trial participation, as well as past use of information sources. Section two comprised six questions the need for services to enhance access to cancer clinical trial information.

3. Response Analysis

The respondents' demographic characteristics were summarized using descriptive statistics. For each survey item, the proportion of respondents selecting each option was calculated and presented quantitatively. For some items, participants could select multiple responses. In these cases, the proportion of first-priority responses—indicating the most critical factors identified by the respondents—was calculated and presented. Additionally, the cumulative proportions of all selected responses were calculated to capture the broader range of reported challenges or barriers. FGIs responses were transcribed and thematically analyzed

to identify key themes.

Results

1. Responses from Medical Oncologists

Among the respondents, 73% worked at tertiary hospitals, whereas 27% were employed at secondary hospitals (below-tertiary hospitals in the Korean healthcare system). Regarding oncology experience, 65% of respondents reported having over 10 years of experience in cancer care and 33% reported over 15 years. The primary cancer types treated by the respondents varied widely. Notably, 98% of participants indicated prior participation in clinical trials. The overall distribution and characteristics of the respondents are summarized in Table 1.

1) Medical Oncologists' Sources of Clinical Trial Information

The KCSG disease committee meeting was the most frequently used channel for accessing clinical trial information, cited by 43.0% of the respondents. This was followed by ClinicalTrials.gov, the trial registry managed by the U.S. National Institutes of Health (NIH) at 22.0%. The KCSG website and personal communication with colleagues were cited by 15.0% of the respondents. Although South Korea offers platforms, such as the Ministry of Food and Drug Safety Integrated Drug Information System and the Clinical Research Information Service (CRIS) managed by the Korea Disease Control and Prevention Agency's National Institute of Health, their usage rates are notably low (Fig. 1). More than 90% of oncologists identified the primary limitations of existing platforms as the lack of real-time updates on trial enrollment status and insufficient access to comprehensive trial information, including eligibility criteria, stages, and treatment settings.

2) Challenges and Barriers in Referring Patients for Clinical Trial Enrollment

While 98.0% of the respondents expressed a willingness to refer patients to other hospitals for appropriate clinical trials, indicating a generally positive attitude toward patient referrals, 75.6% reported instances in which they were unable to complete or had to abandon the referral process (S2 Fig). The primary challenge cited by 22.0% (based on first-priority responses) was having insufficient information to assess trial-patient suitability despite awareness of the existence of the trial. Another key issue was the lack of knowledge regarding where to find information on ongoing trials (16.0%), reflecting a more fundamental barrier to trial awareness. Other difficulties included patient ineligibility after referral (11.0%). Although cited less frequently as a first-priority issue, concerns such as treatment delays while awaiting trial participation (43.0%), the complexity of the referral process (33.0%), and challenges in contacting principal investigators (24.0%) were prominent in the cumulative responses, indicating broader dissatisfaction with these aspects (S3 Fig).

2. Responses from Patients and Caregivers

1) Awareness and Participation in Clinical Trials

The characteristics of patient and caregiver respondents are summarized in Table 2. Among all respondents, 86% (n=172) were aware of clinical trials, as shown in Fig. 2A. However, of those aware, only 23.3% (n=40) had previously participated, indicating a relatively low participation rate despite high awareness (S1 Table). Among these 40 respondents, 95.0% reported having received a recommendation to do so. In contrast, only 15.2% of those who were aware of clinical trials but had never participated (n=132) reported receiving such a recommendation. This finding suggests that recommendations from health care providers play

a crucial role in bridging the gap between clinical trial awareness and participation. Notably, among respondents who were both aware of and had participated in clinical trials (n=40), 92.5% learned about trials through provider recommendations, with 37.5% citing this as their primary reason for participation (Fig. 2B).

2) Difficulties in Accessing Clinical Trial Information

Among the respondents who searched for clinical trial information, 51.5% reported difficulties, while 30.3% gave a neutral response, indicating that they did not find the process easy (Fig. 3A). Overall, 81.8% did not describe their experiences as easy. The primary reasons included not knowing where or how to search for information (57.4%), difficulty understanding the content (48.1%), insufficient or unavailable information (46.3%), and the inability to search for detailed information (42.6%) (Fig. 3B). When asked about sources used to independently search for clinical trial information beyond explanations provided by their healthcare providers, 49.4% indicated a reliance on general search engines such as domestic portals. In contrast, the use of specialized platforms such as the KCSG website, the Ministry of Food and Drug Safety patient-centered clinical trial portal, or Google was quite low (S4 Fig).

3) Future Willingness for Clinical Trial Participation

Among the respondents (n=200), 58.0% expressed a willingness to participate in future clinical trials (Fig. 4A). Notably, 50% indicated a willingness to travel to other regions if a relevant trial was available, reflecting an overall positive attitude toward trial participation (Fig. 4B). The primary motivations included early access to new treatments (48.3%), additional medical benefits (34.5%), physician recommendations or contributions to medical

advancements (29.3%), and financial incentive (16.4%) such as reduced medical costs or travel support (Fig. 4C).

4) Focus Group Interview

The results of the FGIs conducted with patients and caregivers were largely consistent with the quantitative survey findings, and the key themes are presented separately (S5 Table). Briefly, participants exhibited a generally positive and proactive attitude toward clinical trial participation and placed particular importance on physicians' recommendations. However, they also reported substantial difficulties in accessing the necessary information, which appears to be a major barrier to enrollment.

Discussion

This survey investigated the perspectives of medical oncologists and patients/caregivers on clinical trials, with a particular focus on barriers to physician referral and patient participation. While medical oncologists had positive attitudes and substantial prior experience, 76% reported being unable to refer eligible patients because of inadequate trial information systems. The existing online platforms were deemed insufficient. Although 86% of patients and caregivers were aware of the clinical trials, only 23% participated. Most participants relied on medical oncologists for trial information, indicating that the low participation rates may be attributed to limited referral systems and a lack of alternative information sources. Taken together, the most significant barriers to efficient clinical trial enrollment for both physicians and patients are difficulty in accessing trial information and the lack of an effective referral system. Although many platforms provide clinical trial information, programs specifically designed to facilitate interhospital referrals and offer real-time updates

on trial enrollment statuses for healthcare professionals and patients remain rare. In Canada, a pilot program featuring the digital platform named the Clinical Trials Navigator (CTN) was implemented to enhance access to clinical trial information and facilitate enrollment by both patients and healthcare providers [5]. The program has significantly reduced referral times and improved access to clinical trial information, thereby demonstrating promising results. However, the primary goal of the CTN initiative was to streamline the referral process from community hospitals to larger institutions, where trials are conducted more frequently. While many previous studies have emphasized the importance of referral systems, they have primarily focused on promoting referrals from community hospitals or primary care physicians to tertiary care or academic hospitals [6-8]. In contrast, our findings reveal an unmet need for an interinstitutional referral system, even among academic medical centers, where the majority of our surveyed physicians already have extensive trial experience and actively participate in research. In South Korea, most cancer treatments, including chemotherapy, are provided at university hospitals, and the types of ongoing clinical trials vary between institutions. Therefore, facilitating referrals between academic institutions is essential.

From the patient and caregiver perspectives, one of the most commonly reported barriers to patient participation in clinical trials has traditionally been regarded as the negative perception of clinical trials, including financial burdens and concerns about side effects [7-10]. However, more than half of the respondents (58%) expressed a willingness to participate in clinical trials, highlighting that negative perceptions are no longer as a significant barrier as they were previously. In our patient and caregiver survey, despite positive attitudes toward clinical trials, the primary barrier to participation was a lack of information. According to the survey, the clinical trial participants relied entirely on their treating oncologists for trial-related information. However, as physicians themselves report insufficient knowledge regarding trials

conducted at other institutions, the information provided by individual oncologists may inevitably be limited. Additionally, patients may seek further details from alternative sources even after receiving initial information from their primary physicians. Based on survey data, the KCSG is currently establishing an electronic referral system for medical oncologists to search for eligible clinical trials at other institutions, submit referral requests, or directly communicate with the principal investigator (PI) of the trial. Once completed and widely adopted, this system is expected to significantly enhance clinical trial enrollment rates in Korea and ultimately improve patient outcomes. An important point is that patients, as non-medical professionals, require plain language for better understanding. Additionally, accurate and accessible translations in their native languages are essential for multinational multicenter trials. In particular, for older adults, even well-designed information may remain inaccessible due to limited digital literacy and the digital divide, both of which can serve as substantial barriers to accessing clinical trial information.

This study has several limitations. First, the survey was not initially designed for academic research, but was conducted as part of a baseline investigation aimed at promoting clinical trial enrollment. Consequently, their academic rigor may have been compromised. However, the inclusion of both patients and caregivers, as well as the utilization of FGIs for in-depth exploration, significantly enhanced the value of our findings. Second, the number of physician respondents was predetermined and capped at 100, which may have introduced selection bias, potentially favoring individuals with a more positive attitude toward clinical trials. Third, the accuracy of survey responses, particularly from patients and caregivers, may have been influenced by recall bias, as participants may not have precisely recalled their experiences or information received during past clinical trial discussions. Finally, the reliance

on self-reported data could introduce a social desirability bias, especially for oncologists who may feel inclined to portray their attitudes and practices more favorably than they actually are.

In conclusion, this survey highlighted the key barriers to clinical trial enrollment from the perspectives of medical oncologists, patients, and caregivers in South Korea. Despite their positive attitudes, oncologists face challenges due to limited access to updated and comprehensive trial information. Patients and their caregivers rely heavily on their physicians for trial details, indicating the need for more accessible and user-friendly sources of information. Implementing an interinstitutional referral system and enhancing patient education through reliable platforms could improve trial enrollment and outcomes.

Ethical Statement

As this study was a secondary analysis of a survey originally conducted for practical purposes rather than as a research study, prior review or approval by an Institutional Review Board (IRB) was not required.

Author Contributions

Conceived and designed the analysis: Maeng CH, Park I, Lee IH, An HJ, Shim HJ, Lee SC.

Collected the data: Maeng CH, Park I.

Contributed data or analysis tools: Maeng CH, Lee SC.

Performed the analysis: Maeng CH, Lee IH, An HJ, Shim HJ, Lee SC.

Wrote the paper: Maeng CH.

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Conflict of Interest

Conflict of interest relevant to this article was not reported.

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References

1. Bray F, Laversanne M, Sung H, Ferlay J, Siegel RL, Soerjomataram I, et al. Global cancer statistics 2022: GLOBOCAN estimates of incidence and mortality worldwide for 36 cancers in 185 countries. *CA Cancer J Clin.* 2024;74:229-63.
2. Korea VSIDS, Noh H, Seo J, Lee S, Yi N, Park S, et al. Cause-of-death statistics in 2020 in the Republic of Korea. *J Korean Med Assoc.* 2023;66:132-42.
3. Park EH, Jung KW, Park NJ, Kang MJ, Yun EH, Kim HJ, et al. Cancer Statistics in Korea: Incidence, Mortality, Survival, and Prevalence in 2021. *Cancer Res Treat.* 2024;56:357-71.
4. Siegel RL, Giaquinto AN, Jemal A. Cancer statistics, 2024. *CA Cancer J Clin.* 2024;74:12-49.
5. Hamm C, Cavallo-Medved D, Moudgil D, McGrath L, Huang J, Li Y, et al. Addressing the Barriers to Clinical Trials Accrual in Community Cancer Centres Using a National Clinical Trials Navigator: A Cross-Sectional Analysis. *Cancer Control.* 2022;29:10732748221130164.
6. Baer AR, Michaels M, Good MJ, Schapira L. Engaging referring physicians in the clinical trial process. *J Oncol Pract.* 2012;8:e8-e10.
7. Kumar G, Chaudhary P, Quinn A, Su D. Barriers for cancer clinical trial enrollment: A qualitative study of the perspectives of healthcare providers. *Contemp Clin Trials Commun.* 2022;28:100939.
8. Ebrahimi H, Megally S, Plotkin E, Shivakumar L, Salgia NJ, Zengin ZB, et al. Barriers to Clinical Trial Implementation Among Community Care Centers. *JAMA Network Open.* 2024;7:e248739-e.
9. Wong AR, Sun V, George K, Liu J, Padam S, Chen BA, et al. Barriers to Participation in Therapeutic Clinical Trials as Perceived by Community Oncologists. *JCO Oncol Pract.* 2020;16:e849-e58.
10. Mills EJ, Seely D, Rachlis B, Griffith L, Wu P, Wilson K, et al. Barriers to participation in clinical trials of cancer: a meta-analysis and systematic review of patient-reported factors. *Lancet Oncol.* 2006;7:141-8.

Table 1. Characteristics of medical professional respondents

	n	%
Type of healthcare institution		
Academic center (Tertiary hospital)	73	73.0
General hospital (secondary hospital)	27	27.0
Specialist division (<i>multiple answers</i>)		
hepatobiliary	34	34.0
colorectal	37	37.0
head and neck, esophageal	30	30.0
hematologic malignancy	26	26.0
genitourinary	26	26.0
gynecology	18	18.0
palliative	36	36.0
gastric	30	30.0
breast	38	38.0
lung	40	40.0
rare cancer	32	32.0
miscellany	6	6.0
Cancer care experience		
< 10 yr	35	35.0
10 ≤ yr < 15	32	32.0
≥ 15 yr	33	33.0
Clinical Trial Participation Experience		
previous participation	98	98.0
considered but never participated	1	1.0
never participated	1	1.0
Clinical Trial Experience as Investigator		
< 10 yr	41	41.0
10 ≤ yr < 15	35	35.0
≥ 15 yr	22	22.0
never participated	2	2.0
Current Work Location		
Seoul	34	34.0
Other regions	66	66.0
Total	100	100.0

Table 2. Characteristics of patient and caregiver respondents

Group Classification	n	%
Respondent type		
Patients		
Caregivers		
Awareness of Clinical Trials		
Aware (heard of or clearly aware)	172	86.0
Unaware	28	14.0
Experience with Clinical Trials^{a)}		
Experienced	40	23.3
Inexperienced	132	76.7
Sex		
Male	100	50.0
Female	100	50.0
Age		
20s	8	4.0
30s	26	13.0
40s	25	12.5
50s	57	28.5
60s	54	27.0
70s or older	30	15.0
Residential Area		
Seoul	24	12.0
Other regions	176	88.0
Location of treating hospital		
Seoul	77	38.5
Other regions	123	61.5
Total	200	100.0

^{a)}Based on respondents who were aware of clinical trials (n=172).

CANCER RESEARCH AND TREATMENT (CRT)

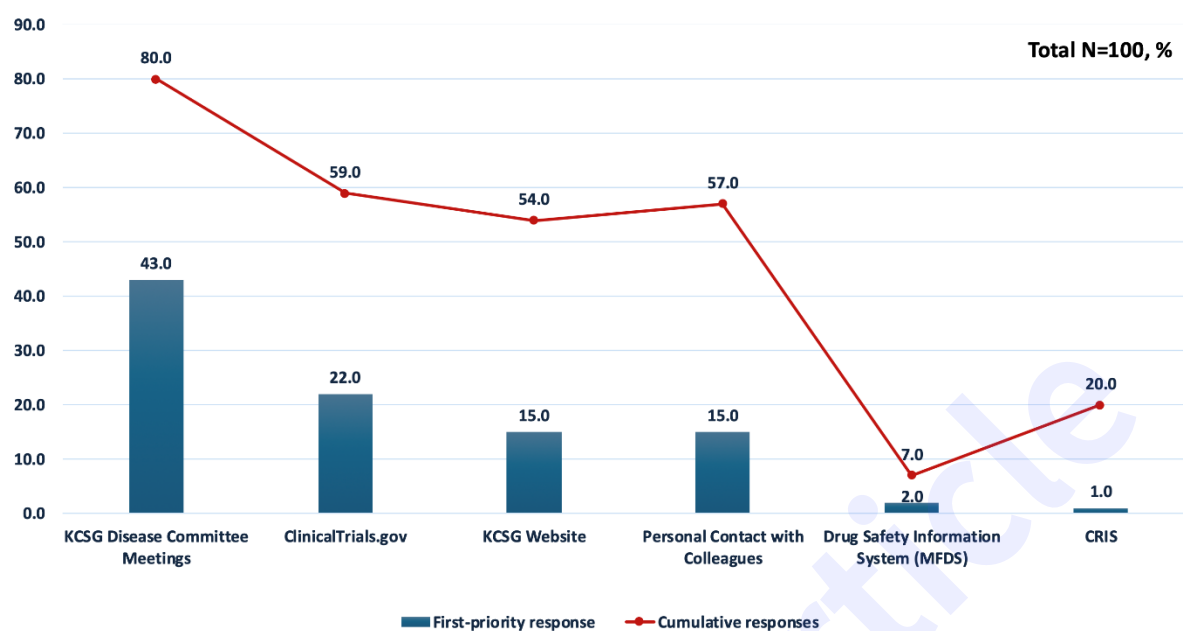
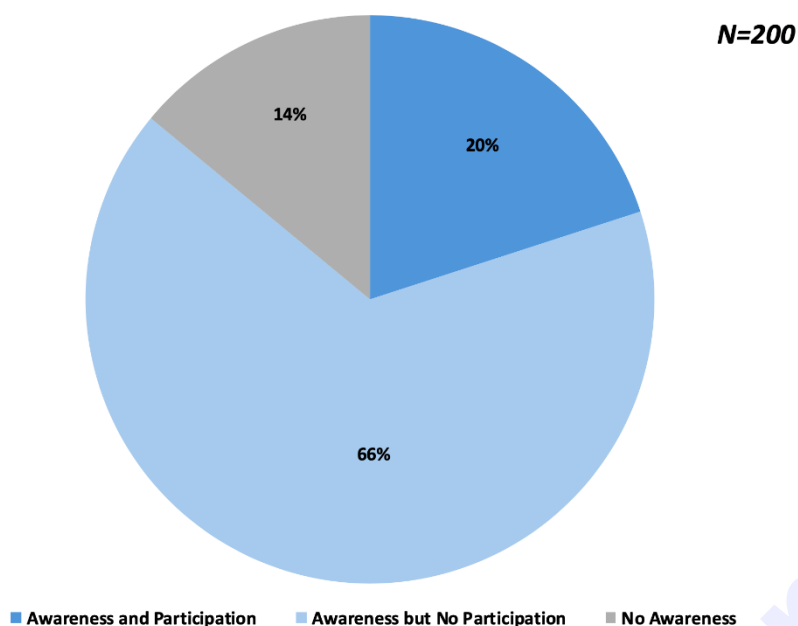


Fig. 1. Medical oncologists' sources of clinical trial Information. KCSG, Korean Cancer Study Group; MFDS, Ministry of Food and Drug Safety; CRIS: Clinical Research Information Service.

(A)



(B)

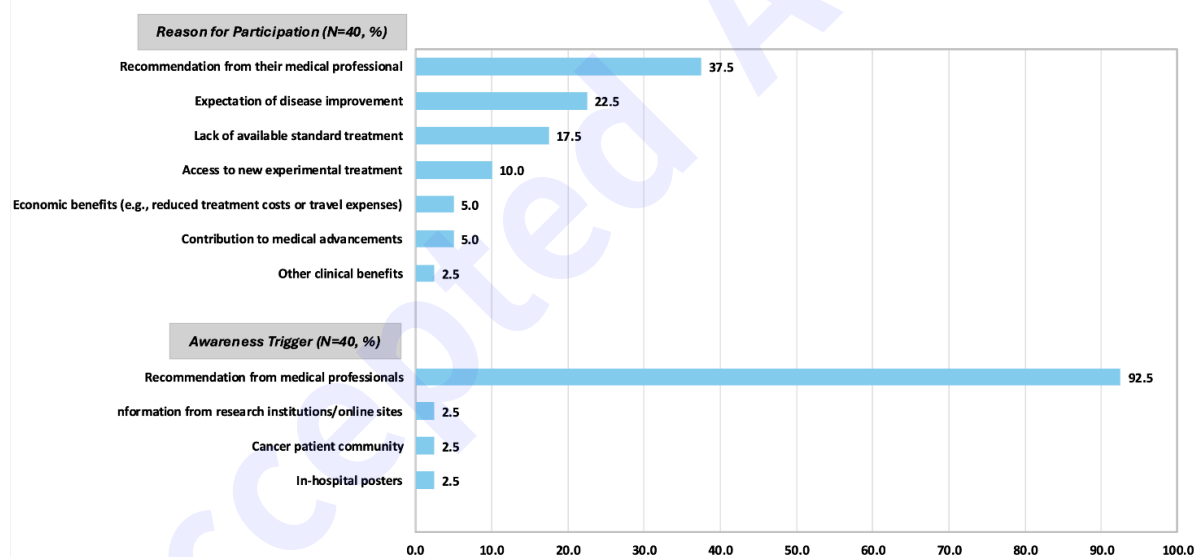
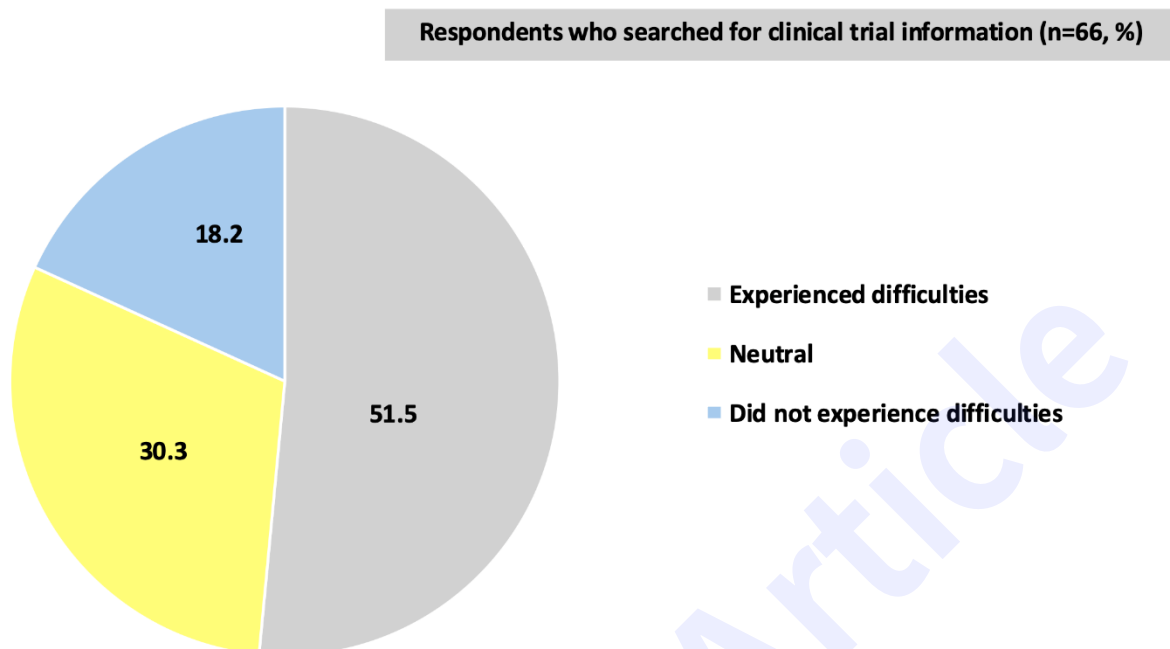


Fig. 2. Patient or caregiver awareness and participation in clinical trials. (A) Awareness and participation status (n=200), (B) Triggers and reasons among clinical trial-aware participants (n=40).

(A)



(B)

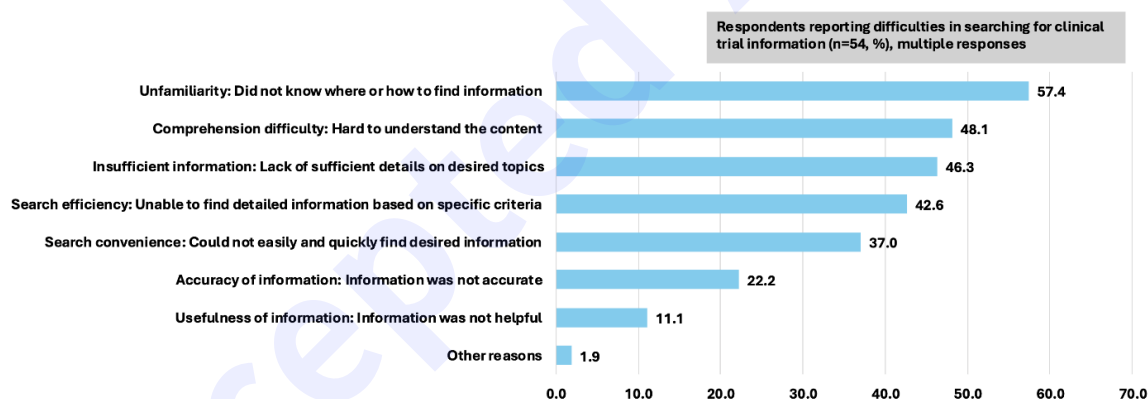


Fig. 3. Difficulties in accessing clinical trial information and reasons for the difficulties. (A) Difficulties in obtaining information for clinical trial participation (n=66), (B) Reasons for difficulties in obtaining clinical trial information (n=54).

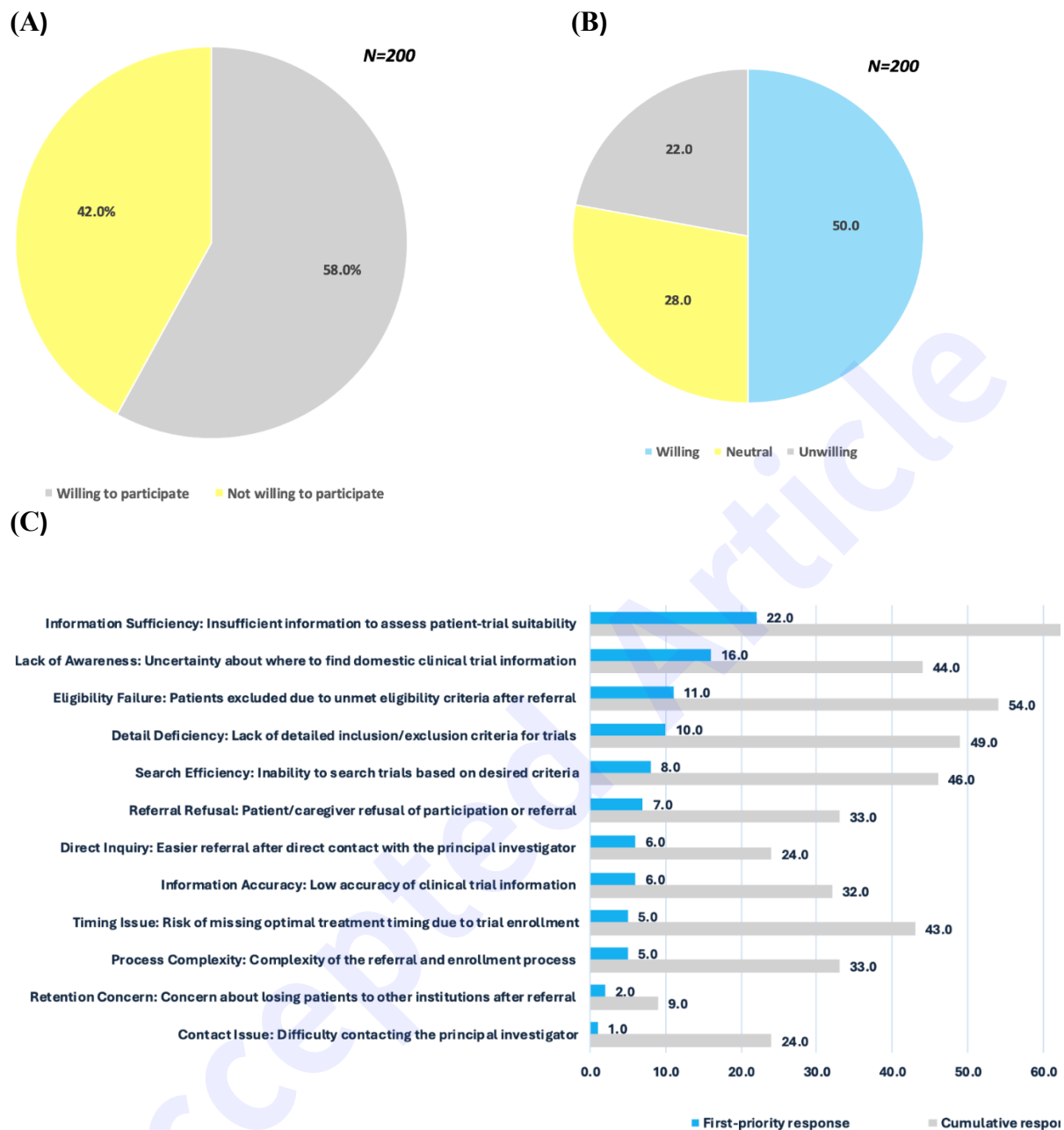
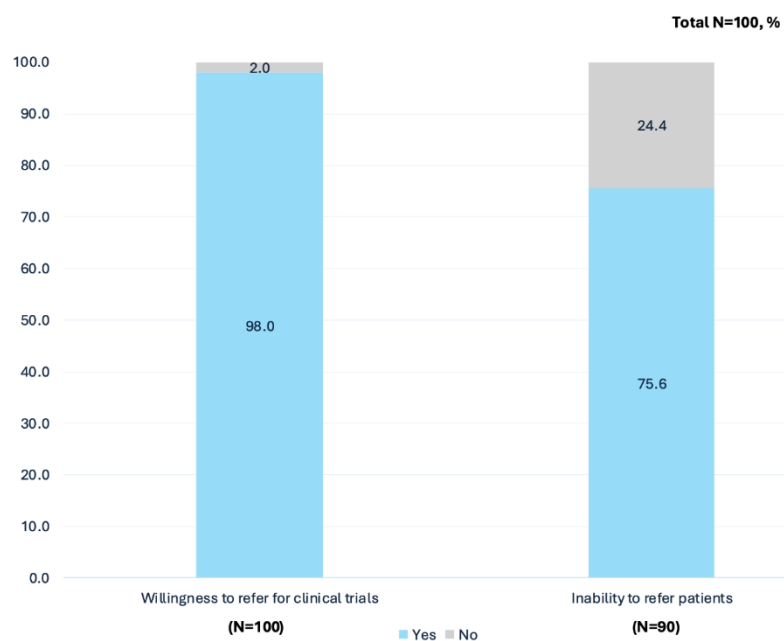


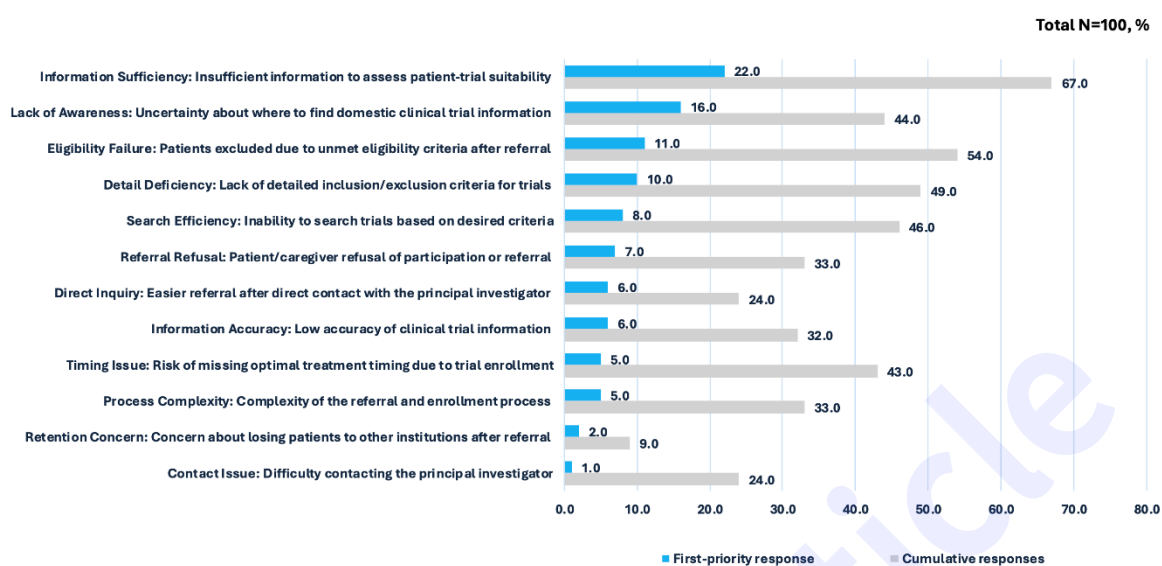
Fig. 4. Future willingness to participate in clinical trials and regional considerations. (A) Future willingness to participate in clinical trials, (B) Willingness to participate in out-of-region trials, (C) Reasons for participation.

S1 Table. Experience of receiving recommendations for clinical trial participation among clinical trial-aware participants (n=172, %)

	Total (n)	Category (n)		Clinical Trial Participation (n)	
		Patients	Caregivers	Participated	Not participated
	172	84	88	40	132
Received a recommendation for clinical trial participation (%)	33.7	34.5	33.0	95.0	15.2
Did not receive a recommendation for clinical trial participation (%)	66.3	65.5	67.0	5.0	84.8

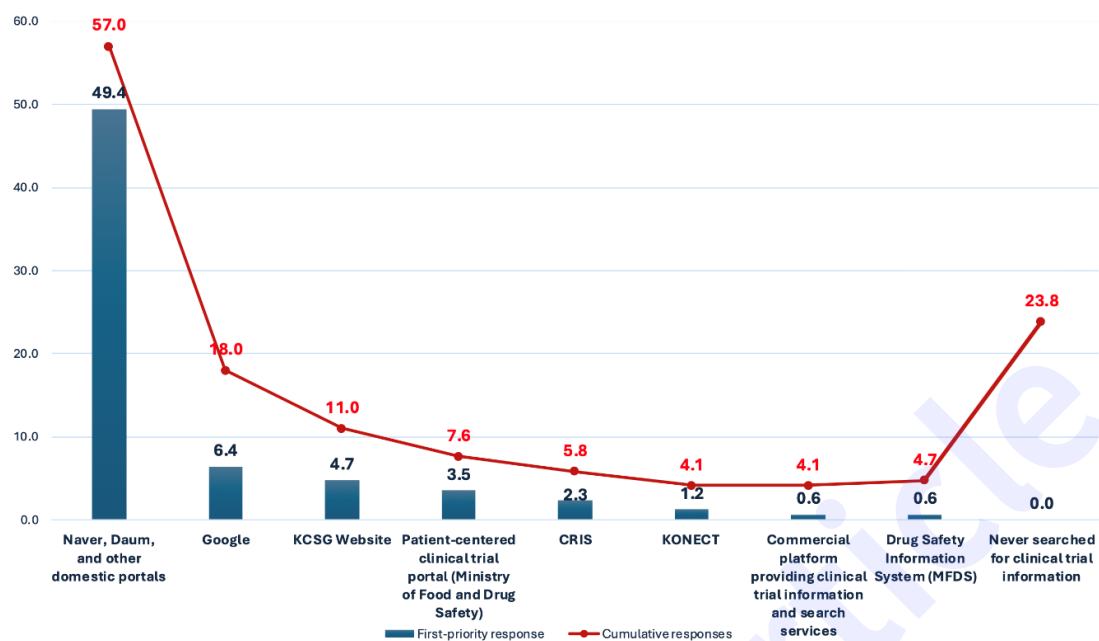


S2 Fig. Referral willingness and experience of inability to refer.



S3 Fig. Barriers and difficulties in patient referral for clinical trial participation.

CANCER RESEARCH AND TREATMENT (CRT)



Abbreviation: KCSG (Korean Cancer Study Group); MFDS, Ministry of Food and Drug Safety; KONECT, Korea National Enterprise for Clinical Trials; CRIS, Clinical Research Information Service.

S4 Fig. Channels for accessing clinical trial information.

S5 Table. Focus Group Interview (FGI) summary**I. FGI method**

To complement the quantitative survey results and gain deeper insights into the perceptions of cancer clinical trials and related information services, a focus group interview (FGI) was conducted with patients and caregivers. The session was held virtually on August 30, 2022, and was moderated by an independent facilitator using a semi-structured discussion guide. Six participants, both clinical trial participants and non-participants, were recruited voluntarily through the Korean Cancer Study Group (KCSG). Participants had varying degrees of experience in searching for clinical trial information; at least three had previously attempted to obtain information through online or mobile platforms. The interview lasted approximately 120 minutes and was recorded, transcribed, and thematically analyzed.

II. FGI findings**1. Perceptions of clinical trials**

Participants expressed a dual perception of clinical trials—marked by both fear and hope. While many voiced concerns about potential adverse effects, uncertainty, and added burdens. Others viewed clinical trials as a final opportunity, a “ray of hope,” or “the best option” when conventional treatments had failed. Several respondents emphasized that while the term “clinical trial” initially evoked anxiety, it gradually came to symbolize possibility and recovery. As one participant stated, “At first I thought clinical trials meant the end, but then I heard of people improving and decided to participate.”

2. Barriers to participation

Several systemic and informational barriers were identified. Participants frequently reported difficulty locating relevant and comprehensible information. They noted that trial-related details were often filled with technical language or written in English, making it hard for laypersons to understand. Additionally, platforms such as government databases or KCSG were largely unknown to participants, who instead relied on portal sites (e.g., Naver), online forums, or word-of-mouth sources. Information was often outdated, incomplete, or not sufficiently tailored to individual cancer type, treatment history, or stage. Some expressed frustration at not knowing whether a trial was still enrolling or whether they would be eligible.

Other common difficulties included long waiting times, burdensome screening procedures, and challenges in aligning trial-related visits with personal or hospital schedules.
3. Information-seeking behavior
Most participants began looking for clinical trial information only after receiving a recommendation from their physician. A consistent theme across interviews was the pivotal role of attending physicians in motivating participation. Respondents expressed deep trust in their doctors' judgment, stating that the decision to participate was largely influenced by their doctor's expertise and encouragement. As one participant remarked, "I follow my doctor's advice because he knows my case best—I trust him to recommend what's right." Others similarly noted that it was only after the physician's explanation that they considered clinical trial participation seriously. Despite this reliance, many participants found the search process overwhelming. Comments included: "I don't even know where to begin searching," and "Even when I search, I can't understand the content because it's full of jargon." Several said they had never searched for trials proactively. Some described printing out clinical trial information and bringing it to their physician for interpretation.
4. Motivators for participation
Physician recommendation emerged as the most cited reason for clinical trial participation. Trust in the attending physician's expertise and familiarity with the patient's condition provided reassurance. Additionally, the lack of other treatment options, hope for symptom improvement, and the potential reduction in financial burden of high-cost drugs (e.g., targeted therapies not covered by insurance) were motivating factors. One caregiver noted, "The medication was nearly \$5,000 a month—we couldn't afford it. Clinical trials seemed like a way to get help and maybe access a new treatment."
5. Satisfaction with participation
Among those who had participated in trials, several reported positive experiences. Perceived improvements in symptoms, improved mobility, or stabilization of disease led to increased willingness to recommend trial participation to others. A participant shared, "My wife couldn't walk before, but after the trial, she's walking again—it exceeded expectations."
6. Difficulties during participation

FGI participants also highlighted logistical and procedural burdens encountered during enrollment and participation. These included delayed trial initiation, lengthy pre-screening evaluations, repeated biopsies, difficulty with hospital transfers, and long wait times at clinics. The need to coordinate with hospital schedules and the physical toll of travel and testing were cited as major sources of fatigue. One participant said, “We agreed to participate, but my mother’s condition worsened while waiting more than a month for the trial to begin.”

7. Suggestions for improvement

Participants recommended more active physician-initiated promotion of trials, improved accessibility of trial-related information, and user-centered digital platforms. Specific recommendations included establishing a centralized site with plain-language summaries, filters for personalized trial matching, SMS/email alerts for updates, and the placement of educational posters or leaflets in hospital waiting areas. Participants proposed appointment of dedicated coordinators to assist with navigation. Several emphasized that information should be available well in advance—ideally at the time of diagnosis or early treatment—so patients can prepare, rather than searching urgently when few options remain.

8. Policy recommendations

FGI participants emphasized the need for system-level support such as government-backed compensation for side effects, stronger community-based networks among trial participants, and expanded access to membership-based platforms offering structured, continuously updated information. They also expressed interest in mechanisms that offer financial support or guidance about available reimbursement systems.