



Equity in Research: What BAME Voices Reveal About Clinical Trial Participation in the UK

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Abstract

Clinical trials have historically underrepresented racial and ethnic minorities, women, older adults, and those with comorbidities, limiting generalizability of results. This study explored motivations and barriers to participation among BAME populations to inform inclusive recruitment strategies. Adults aged 18+ from diverse BAME backgrounds were surveyed via community organisations, social media, and local health services. Key motivators for participation included contributing to medical advancement (22.8%), helping others (9.71%), and access to new treatments (6.71%), while compensation was least cited (3.34%). Barriers included fear of side effects (35.67%), lack of information (33.33%), time constraints (24.64%), and distrust in pharmaceutical (19.30%) and medical systems (18.3%). Encouragement factors were assurance of safety (79.44%), clarity on trial purpose (78.32%), clinician recommendations (45%), peer participation (45%), and fair compensation (42.78%), with representation cited by 38.9%. Information sources were primarily word of mouth (59.78%), social media (58.66%), and print media (56.42%), with community centres (48.04%) and radio (36.31%) also contributing. Findings highlight the need for recruitment strategies that combine peer networks, community ambassadors, social media, and traditional media, while emphasizing safety, transparency, clinician/peer endorsements, ethical compensation, and diversity. These approaches support ethical, inclusive, and effective trial engagement.

Keywords: Clinical trial participation, BAME recruitment barriers, Motivators for research participation, Health disparities, Community engagement strategies, Trust in healthcare system

Introduction

Diversity in clinical trials is a critical element that impacts the generalisability and effectiveness of medical research findings. Historically, clinical trials have often underrepresented various demographic groups, including racial and ethnic minorities, women, older adults, and individuals with comorbidities. This lack of representation can lead to skewed data that may not accurately reflect the efficacy and safety of treatments across diverse populations, ultimately affecting patient care and health outcomes. The importance of diversity in clinical trials has gained recognition in recent years, particularly as healthcare disparities continue to persist. According to the National Institutes of Health (NIH), diverse populations experience different disease burdens and treatment responses [1]. For instance, genetic, environmental, and lifestyle factors can vary significantly across different demographic groups, influencing both the progression of diseases and the effectiveness of therapeutic interventions [2]. Therefore, including a representative sample in clinical trials is essential for understanding these variations and ensuring that all patients receive optimal care. Moreover, regulatory bodies, such as the Food and Drug Administration (FDA), have emphasised the need for diversity in clinical research. The FDA's guidance on enhancing the diversity of clinical trial populations underlines the imperative to include underrepresented groups to ensure that clinical findings are applicable to the general population [3]. This is particularly relevant in the context of chronic diseases, where treatment responses can vary significantly across demographic groups, leading to potential inequalities in health outcomes. Research has shown that diverse clinical trial participation can lead to better health outcomes. For example, a study published in the Journal of Clinical Oncology found that inclusive trials with diverse populations yielded more comprehensive data on the efficacy of cancer treatments, ultimately leading to improved survival rates among underrepresented groups [4]. Furthermore, the inclusion of diverse groups in clinical trials fosters trust in the medical research community, as it reflects a commitment to addressing health disparities and improving health equity. Clinical trials play a vital role in advancing medical research and improving healthcare outcomes. However, it is essential to address the lack of diversity in these trials to ensure the safety, effectiveness, and equitable access to healthcare for all individuals. Clinical trials are research studies that involve human participants to evaluate the safety and effectiveness of medical interventions, such as new drugs, vaccines, or medical devices. Clinical trials provide evidence-based data that guide medical decision-making and contribute to the development of innovative treatments. The results of clinical trials have a direct impact on patient care, regulatory decisions, and healthcare policies. Historically, clinical trials have predominantly included participants from specific racial and ethnic backgrounds, often excluding minority populations. The underrepresentation of diverse populations creates a significant gap in our understanding of the safety, efficacy, and potential side

effects of medical interventions for different racial and ethnic groups. Factors contributing to the lack of diversity in clinical trials include socioeconomic disparities, language barriers, mistrust, and inadequate recruitment strategies. Furthermore, the striking and persistent under-representation of minority racial and ethnic groups in clinical trials is harmful. In the USA, minority racial and ethnic groups comprise nearly 40% of the population; however, 75% of the 32,000 participants in the trials of 53 novel drugs approved in 2020 by the US Food and Drug Administration (FDA) were White [5-7].

The inclusion of diverse participants helps ensure that findings are applicable across different demographics, addressing safety, bias, and assurance in clinical trials. Safety is paramount in clinical trials, as they aim to evaluate the risks and benefits of new interventions. The diversity of participants is crucial for understanding how different populations respond to treatments. Genetic, environmental, and cultural factors can influence drug metabolism, efficacy, and safety profiles. For instance, a medication that works well in a predominantly Caucasian population may have adverse effects or reduced effectiveness in non-white populations due to genetic variations. To enhance safety, regulatory bodies like the FDA emphasise the importance of including underrepresented groups in trials. This involves proactive recruitment strategies, such as community engagement and partnerships with local organisations, to build trust and encourage participation among diverse populations. Additionally, ongoing monitoring for adverse effects across different demographic groups during the trial is essential to ensure that all participants are protected. Bias in clinical trials can arise from various sources, including selection bias, measurement bias, and reporting bias. The lack of diversity in clinical trial populations often leads to skewed results that do not accurately reflect the broader population [7-11].

For instance, if a trial predominantly includes young, healthy individuals, the findings may not be applicable to older adults or those with comorbidities. To mitigate bias, researchers must implement rigorous protocols that promote diversity in participant recruitment. This includes setting specific diversity targets and utilising stratified sampling techniques to ensure that various demographic groups are adequately represented. Furthermore, researchers should be trained to recognise and combat implicit biases that may affect their approach to trial design and participant engagement. Assurance in clinical trials refers to the confidence that the findings are reliable and applicable to the general population. To achieve this, it is essential to establish robust frameworks for monitoring and evaluating the inclusivity of trials. Regulatory agencies can play a pivotal role by requiring detailed plans for diversity recruitment in trial proposals. Additionally, transparency in reporting is vital for assurance. Researchers should disclose demographic data about trial participants, allowing for independent analysis of the representativeness of the sample. This transparency fosters trust among stakeholders, including participants,

healthcare providers, and the general public. Moreover, conducting post-market studies can provide further assurance by evaluating the long-term safety and efficacy of treatments across diverse populations after they have been approved. These studies help identify any disparities in outcomes and inform future research and clinical practice. Safety, bias, and assurance are interconnected elements that significantly influence the integrity of clinical trials. Ensuring that diverse populations are adequately represented in clinical research is not just a regulatory requirement but a moral imperative. By prioritising diversity, researchers can enhance the safety and applicability of their findings, ultimately leading to more effective and equitable healthcare solutions. As the landscape of clinical research continues to evolve, a commitment to inclusivity will be essential in driving advancements that benefit all segments of society [12-17].

In conclusion, the need for diversity in clinical trials is not merely a matter of ethical obligation; it is essential for advancing medical science and improving patient outcomes across all demographics. Future research must prioritise inclusion to ensure that clinical findings are relevant and beneficial to the entire population. In this study the aim was to provide valuable insights into the motivations and barriers faced by the BAME population regarding participation in clinical trials, ultimately informing strategies to enhance recruitment and engagement in this underrepresented demographic.

Materials and Methods

Study Design

This study employed a cross-sectional survey design to explore the reasons for participation in clinical trials among a sample of 183 individuals from the Black, Asian, and Minority Ethnic (BAME) population. The survey was conducted online to ensure accessibility and convenience for participants.

Participants

The study targeted individuals aged 18 years and older from diverse BAME backgrounds (18 - 24 years, 4.4%; 25 - 34 years, 7.14%; 35 - 44 years, 18.13%; 45 - 54 years, 27.47%; 55 - 64 years, 38.81%; > 65 years, 6.06%). Participants were recruited through community organisations, social media platforms, and local health services. Inclusion criteria stipulated that participants must identify as part of a BAME group and could understand English to complete the survey. Females constituted 46.41% of participants, with 53.59% males. People identified of Black heritage constituted the majority of 87.85%, those that identified of Asian heritage 6.08%, 5.52 identifies as of mixed heritage and 0.55% identified of Arab heritage. Most of the respondents identified as Christian 79.01%, 6.63% identified as Muslim, 2.76 as Hindu, 2.76 as other

and 8.84 and as of no faith.

Survey Instrument

A structured questionnaire was developed specifically for this study using SurveyMonkey. The questionnaire included sections on demographic information, previous experiences with clinical trials, and reasons for participation. Key factors assessed included: Awareness of Clinical Trials: Participants were asked about their knowledge of clinical trials and sources of information, motivations for participation and the importance of various reasons for participating in clinical trials, including altruism, potential health benefits, financial compensation, and access to new treatments and barriers to Participation. Questions were:

- a. Have you ever been asked or considered participating in a clinical trial?
- b. If have participated in a clinical trial, what were the reasons?
- c. If have not participated in a clinical trial, what were the reasons?
- d. What things would encourage you to participate in a clinical trial?
- e. Where would you like to hear or get information about clinical trials?

The participants were also provided a free text to describe, in their opinion, what could be done to improve the participation of non-white populations in clinical trials.

Data Collection

The survey was administered using an online platform, allowing participants to complete the questionnaire at their convenience. Data collection occurred over a four-week period, during which reminders were sent out to encourage participation. Informed consent was secured from all participants prior to survey completion.

Limitations

The study acknowledges potential limitations, including self-selection bias and reliance on self-reported data, which may affect the generalisability of the findings. Additionally, the online nature of the survey may exclude individuals without internet access.

Results

Question: Have you ever been asked or considered participating in a clinical trial? One hundred and seventy-five respondents answered the question, with 36% saying yes and 64% saying no (Figure 1).

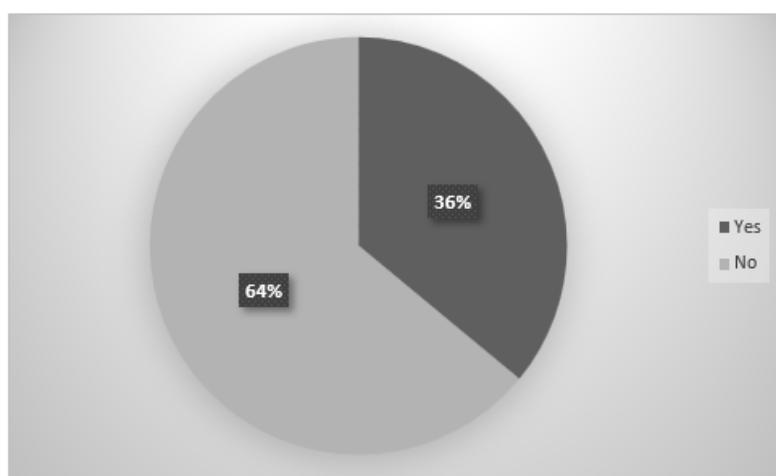


Figure 1

Question: If you have participated in a clinical trial what were the reasons you would consider taking part in a clinical trial? One hundred and seventy-five respondents answered the question, only 27% ticked the reasons with contributing to medical advancement

(22.8%) as being the major reason why the respondents would take part in a clinical trial, followed by helping others (9.71%) and getting or access to new medical treatments (6.71%) and least was compensation (3.34%) (Figure 2).

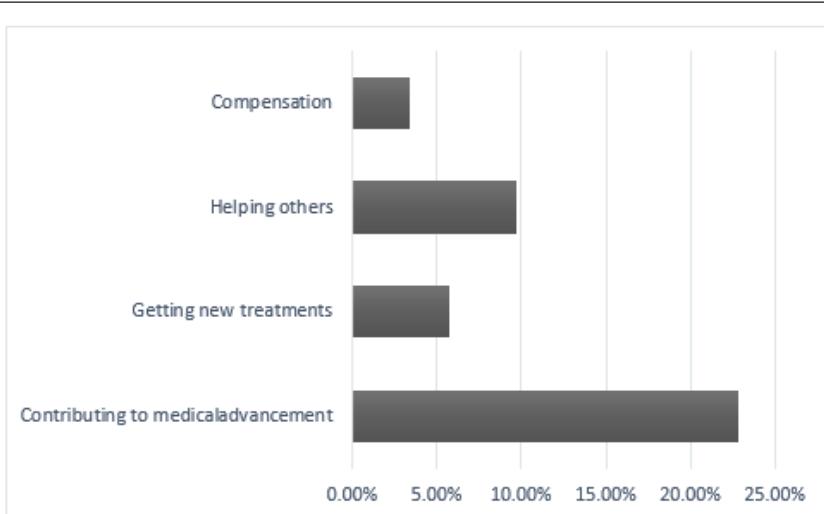


Figure 2

Question: If have not participated in a clinical trial, what were the reasons? One hundred and seventy-one (171) respondents answered the question, 40.35% ticked not applicable. Of the remaining respondents, the primary reason for not participating in clinical trial was the fear of side effects (35.67%), the lack of information (33.33%) then lack of time (24.64%), followed by distrust in the pharmaceutical (19.30%) and medical system (18.3%) with not feeling welcome (9.36%), the least reason for not participating in clinical trial (Figure 3).

Question: What things would encourage you to participate in a clinical trial? One hundred and eighty (180) respondents answered the question, the most important thing was the assurance of safety and minimal side effects (79.44%) and more information on the purpose of the trial (78.32), then the recommendation of healthcare provider (45%), knowing someone else who has participated (45%), followed by compensation (42.78%) and the least seeing participants of my racial background involved (38.9%) (Figure 4).

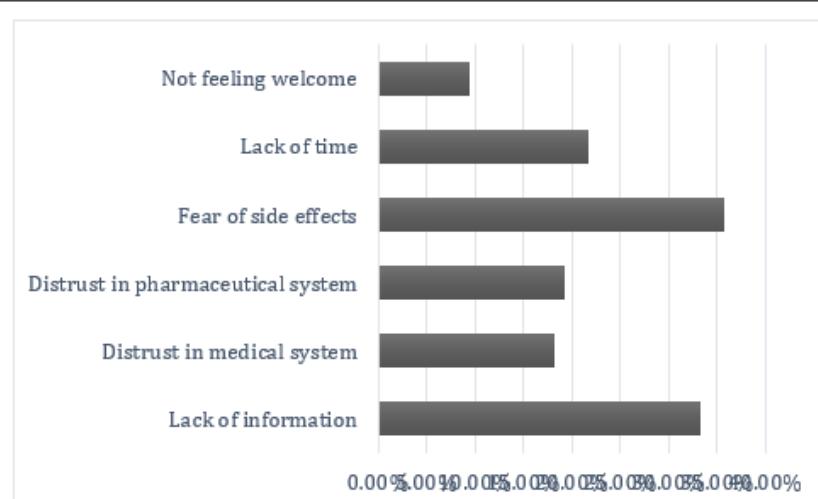


Figure 3

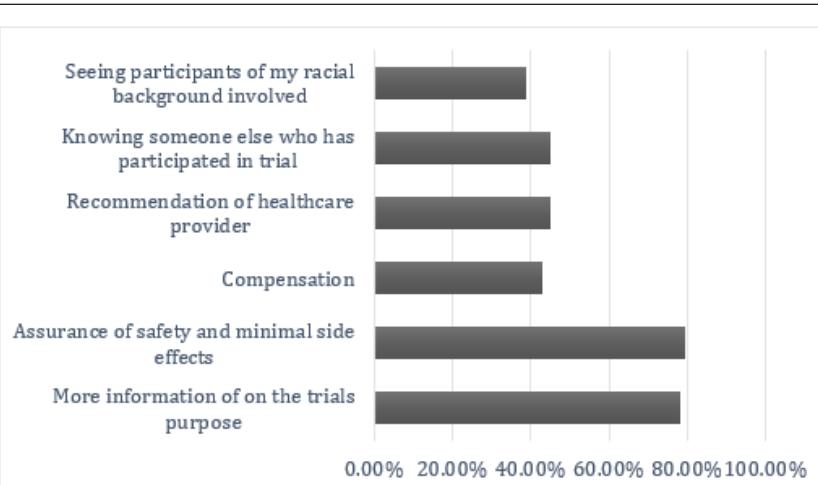


Figure 4

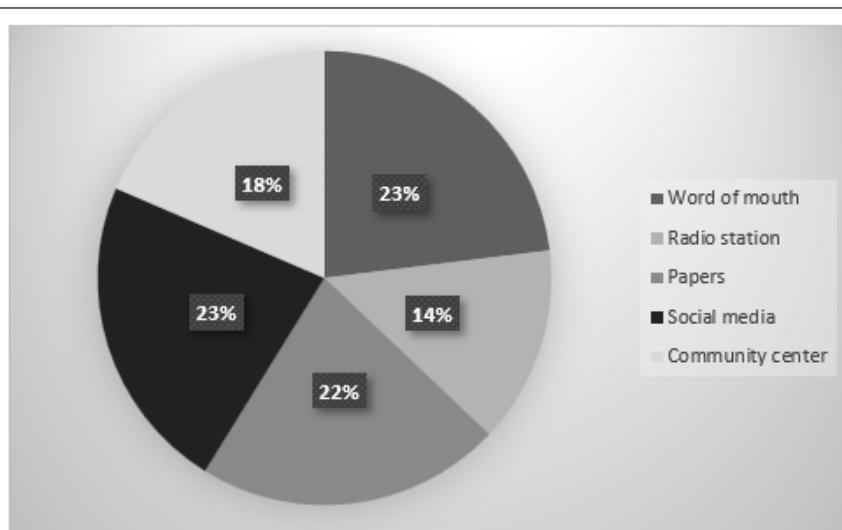
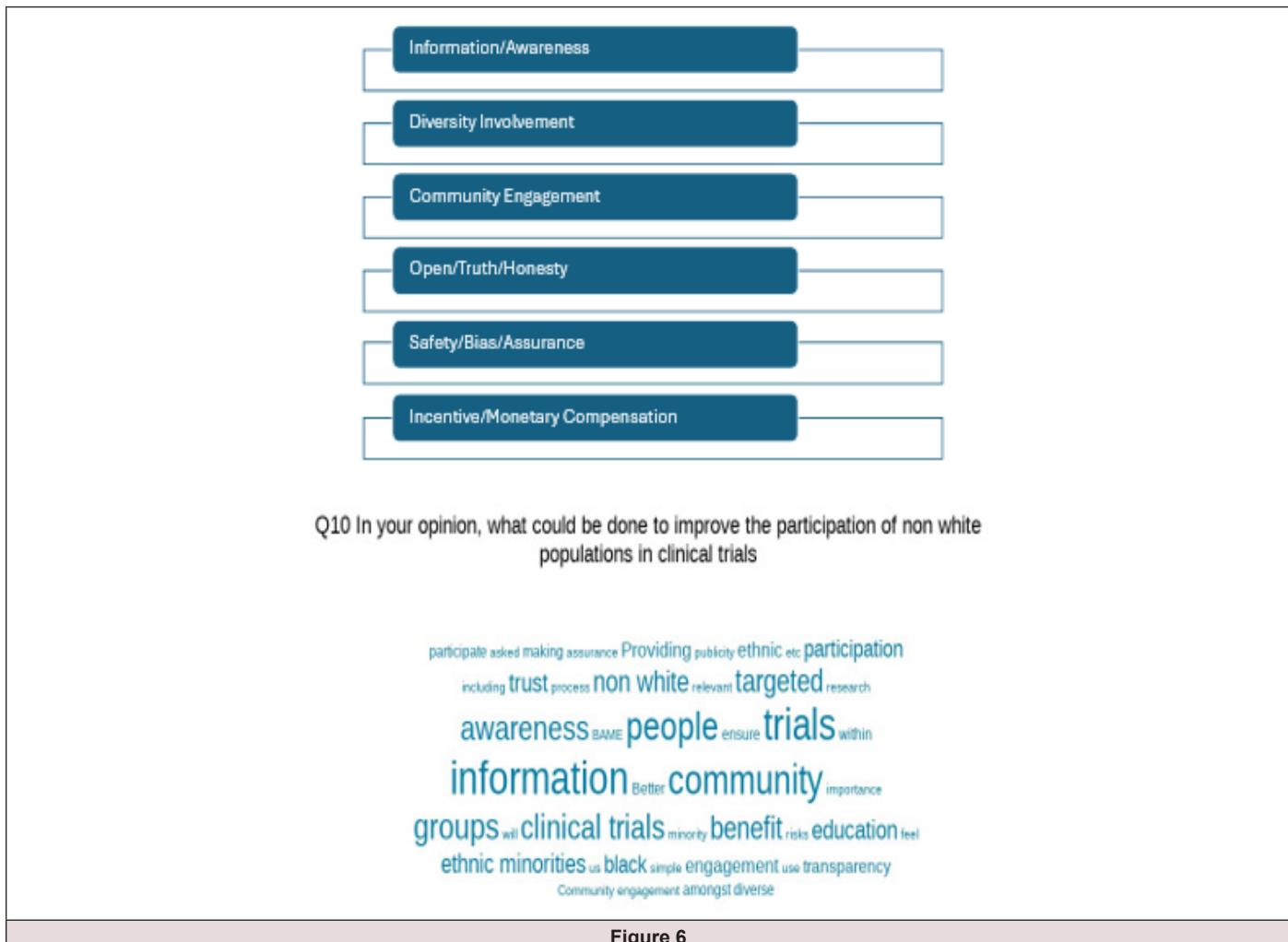


Figure 5



Question: Where would you like to hear or get information about clinical trials? One hundred and eighty (180) respondents answered the question, word of mouth was the most popular (59.78%), followed by social media (58.66%), then papers (56.42%), then community centres (48.04%) and least from radio stations (36.31%) (Figure 5).

Question: In your opinion what could be done to improve the participation of non-white populations in clinical trials? 137 respondents answered the question

Free text responses of 137 respondents fell into these buckets (Figure 6):

Discussion

The study targeted individuals aged 18 years and older from diverse BAME backgrounds (18 - 24 years, 4.4%; 25 - 34 years, 7.14%; 35 - 44 years, 18.13%; 45 - 54 years, 27.47%; 55 - 64 years, 38.81%; > 65 years, 6.06%. Approximately one-third of respondents reported having been asked to participate or having participated in a clinical trial. This reflects a relatively high level

of engagement and awareness, suggesting that clinical research is reaching a broad segment of the population.

Our findings highlight that altruism remains the predominant motivator for clinical trial participation, with nearly one-third of respondents citing either the desire to contribute to medical advancement (22.8%) or to help others (9.71%). This aligns with prior studies describing conditional altruism, where individuals balance personal benefit with a commitment to advancing science and societal good. Access to new medical treatments (6.71%) was also a meaningful incentive, particularly for patients with limited therapeutic options, consistent with evidence that healthcare access and distrust in existing systems can influence enrollment. Interestingly, compensation was the least cited reason (3.34%), reinforcing ethical guidance that financial incentives should remain modest to avoid undue inducement and protect informed consent. Together, these findings suggest that recruitment strategies emphasizing both the societal impact of research and the potential for personal therapeutic benefit may be most effective, while financial incentives play a secondary role. Research consistently shows that altruistic motives dominate clinical trial participation.

McCann et al. describe this as "conditional altruism", where individuals balance personal considerations with a desire to advance science. Similarly, Chin et al. found that participants in HIV vaccine trials often cited altruism and helping others as key reasons for enrollment. These findings reinforce the idea that recruitment messaging should emphasize the societal impact and collective benefit of research [18,19].

Among individuals who had not participated in clinical trials, the most frequently cited barrier was fear of side effects (35.67%), reflecting longstanding concerns about safety and risk perception. This aligns with evidence that apprehension about adverse events is a dominant deterrent to enrollment, particularly in early-phase studies. The lack of information (33.33%) was the second most common reason, underscoring the critical need for transparent communication and accessible trial education materials. Time constraints (24.64%) also emerged as a significant barrier, consistent with studies showing that logistical burdens such as travel, scheduling, and caregiving responsibilities reduce participation [20-22].

In addition, distrust in the pharmaceutical industry (19.30%) and the medical system (18.3%) were reasons to not participate in this study, this underscores systemic challenges of credibility and equity that disproportionately affect minority and underserved populations. Historical abuses, such as the Tuskegee syphilis study, have contributed to long-standing mistrust, which continues to influence perceptions of clinical research today. Studies show that a lack of transparency, perceived exploitation, and inequitable access exacerbate this distrust, limiting participation among communities most in need of representation [23-26].

Although not feeling welcome (9.36%) was the least cited barrier, it highlights subtle but important issues of inclusivity and participant experience. Research demonstrates that cultural insensitivity, lack of representation among research staff, and inadequate community engagement can create environments where individuals feel excluded. Addressing these barriers requires proactive strategies, including culturally competent communication, diverse trial teams, and community partnerships to foster trust and inclusivity. Together, these findings emphasize that rebuilding credibility and ensuring inclusivity are essential for equitable clinical trial participation.

Safety assurance, cited by nearly 80% of respondents, underscores the centrality of risk perception in clinical trial participation. Participants consistently prioritize confidence that adverse effects will be minimized, well-managed, and transparently communicated. This highlights the ethical imperative for robust informed consent processes and clear safety protocols, ensuring that participants understand both potential risks and safeguards. Evidence from systematic reviews confirms that concerns about side effects and safety are the most common barriers to enrollment, and that transparent communication of risk is essential to build trust and encourage participation [27-29].

Information on the purpose of the trial, cited by 78.32% of respondents, highlights participants' strong desire for transparency and contextual understanding. Beyond knowing the procedures, individuals want clarity on the broader scientific and therapeutic goals, including how the trial contributes to medical progress and patient care. This finding underscores the importance of effective communication strategies that emphasize relevance, impact, and rationale. Evidence shows that participants are more likely to enroll when they understand the trial's significance, potential benefits, and contribution to society [30]. Transparent communication not only supports recruitment but also strengthens trust, informed consent, and long-term engagement.

Recommendations from healthcare providers and peer participation (45%) highlight the critical role of trusted relationships and social influence in clinical trial recruitment. Clinician endorsements and peer testimonials have been shown to significantly increase willingness to participate, particularly when combined with educational outreach that addresses safety and trial purpose [31].

Compensation, cited by 42.78% of respondents, emerged as a secondary motivator for clinical trial participation. While financial incentives can help support recruitment, they are not the primary driver compared to safety assurance or transparency. This finding aligns with established ethical guidance, which cautions against undue inducement that could compromise voluntariness or informed consent. Regulatory frameworks emphasize that payments should be fair and proportionate, covering time and inconvenience rather than serving as coercive incentives. Thus, compensation should be positioned as a supportive measure within recruitment strategies, ensuring that participation remains grounded in autonomy and informed decision-making [32].

Representation, though cited by only 38.9% of respondents, remains a meaningful factor in clinical trial participation. Seeing participants of similar racial or ethnic backgrounds can enhance trust, reduce perceived barriers, and foster a sense of belonging particularly among minority and underserved populations. Evidence shows that lack of representation contributes to mistrust and disengagement, while visible inclusivity strengthens confidence in research processes. This finding supports ongoing efforts to improve diversity and inclusivity in clinical trials, not only as a matter of equity but also as a strategy to enhance engagement, trust-building, and generalizability of results [33].

The most cited source of awareness was word of mouth (59.78%), underscoring the dominant role of personal networks and informal conversations in shaping perceptions of clinical research. Evidence shows that peer advocacy, patient testimonials, and community engagement are powerful tools for disseminating trial opportunities, reinforcing the importance of trust and familiarity in health-related decision-making. Social media (58.66%) followed closely, reflecting the growing influence of digital platforms in health communication. While these channels

offer scalability and immediacy, they also require careful curation to ensure accuracy and avoid misinformation. The near parity with word of mouth suggests that digital and interpersonal strategies should be integrated rather than siloed. Printed papers (56.42%) remain significant, particularly for populations valuing traditional media or with limited digital access. Local newspapers, newsletters, and research publications continue to play a role in outreach, highlighting the need for multi-format communication strategies, especially in underserved or older populations. Community centres (48.04%) were also notable, emphasizing the role of local institutions and trusted spaces in health education. These venues provide opportunities for direct engagement, workshops, and culturally tailored messaging, making them especially valuable for populations with lower digital literacy or limited healthcare access. Finally, radio stations (36.31%), though least cited, remain relevant in rural areas, among older adults, or in regions where radio is a primary medium. Its lower ranking suggests that radio should be part of a layered communication strategy, complementing other outreach methods rather than serving as a standalone channel.

Conclusions

The paper highlights two critical domains for improving clinical trial participation: trial design and outreach strategy. In trial design, it emphasises the importance of clear safety communication, transparent purpose, and ethical use of compensation. Trust-building through clinician endorsements and peer testimonials is essential, alongside inclusive recruitment materials that reflect diverse populations. For outreach, the paper advocates a multi-channel approach leveraging peer networks, community ambassadors, and social media while maintaining traditional formats like print and radio. Community centres play a pivotal role in fostering trust and delivering tailored information, ensuring accessibility across varied demographics. Together, these strategies support ethical, inclusive, and effective trial engagement.

Acknowledgement

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Conflict of Interest

None.

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