

Review of the Literature: Primary Barriers and Facilitators to Participation in Clinical Research

Background

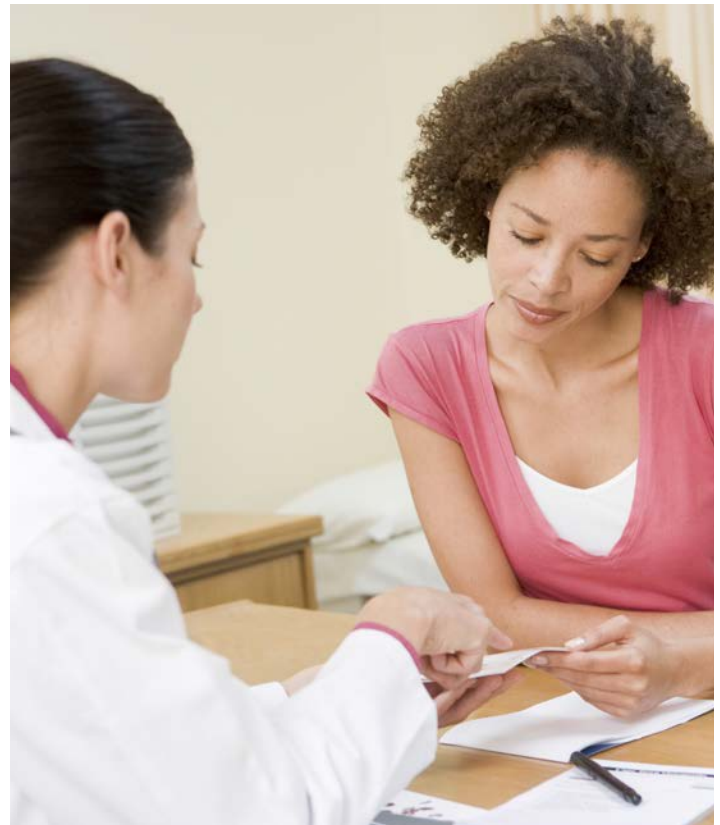
The ongoing challenge of recruiting and retaining volunteers has prompted studies to identify why recruitment and retention can be so difficult and – more importantly – what can be done about it. This section provides a summary of the literature on the barriers and facilitators to recruiting women from diverse backgrounds to [clinical trials](#). Recruitment and retention in [clinical research](#) is complex and influenced by a range of factors that may affect an individual's ability and motivation to participate in a clinical study.

Barriers

Challenges with recruitment and retention are linked to the type of study conducted and by a wide range of factors, including whether the prospective participants already have access to treatment in their community, the potential risks associated with the study, and the amount of travel, number and length of follow-up visits, and invasiveness of the testing.¹ Some of the reasons most often cited for declining participation, especially in clinical trials, include study burden, distrust and wariness of researchers, lack of knowledge and understanding of the clinical process, and fear of risk and randomization. Systematically addressing each of these barriers can help researchers exert a positive effect on successful recruitment and retention.

1. Study burden

The most often cited barrier to participation was related to study burden. When a potential participant has no car and buses and taxis are difficult to access or are too costly, the prospect of traveling to a clinical facility for research purposes may present a formidable obstacle. A study of the participation of gynecological cancer patients in Phase I clinical trials found that participation increased when enrollees lived closer to the hospital where the trial was based. Patients likely weighed the potential benefit of the trial against the time and travel commitments that the study required.² In determining postmenopausal breast cancer



patients' willingness to participate in an acupuncture trial for pain relief, investigators found that among women who declined to enroll, white women were more likely to report that they would not participate because of concerns about transportation.³ Avis and colleagues found that keeping travel time and number of clinical visits to a minimum might increase trial participation.⁴

Women indicated that inconvenience related to securing transportation, along with the associated cost and time, limited their ability to participate in clinical research,^{5,6} as did inconvenient locations and appointments for research visits.^{7,8} Although transportation was a barrier for many study populations, accessing reliable transportation appears to be a greater barrier for older participants and for rural populations. Since rural communities offer fewer transportation options, study recruitment of women living in rural areas may require additional efforts.⁹ Clinical staff noted that extra time was

needed to recruit older women into the trial and that the women relied on caregivers or family members to bring them to visits.¹⁰

Arranging transportation was the most common barrier, but other issues, including child care and time away from work, were also important considerations. As caregivers for dependent children, grandchildren, or aging parents, some women and minority group members have limited free time to participate in research and taking annual or sick leave from work to participate in a study may not be an option. Women identified child care commitments, in addition to transportation, as barriers in multiple research studies.^{11 12 13} Women who declined to participate in a breast cancer risk communication trial most often cited lack of time as the reason for nonparticipation.¹⁴ Lack of time was also a common barrier in a lifestyle intervention for women diagnosed with gestational diabetes.¹⁵

2. Distrust of researchers

Studies suggest that women and minorities are less trusting of researchers and research institutions and that minority populations exhibit lower rates of study participation than white populations.¹⁶ Historically, the typical research participant was a white male. History, education, culture, language, socioeconomic status, geography, racial identity, prejudice, and paternalism are implicated in the underrepresentation of women and minorities in clinical research.^{17 18} The Tuskegee syphilis study and other instances of unethical research events have contributed to major mistrust of the research community among minority populations. Minority communities still strongly believe that participating in a clinical trial could actually worsen one's health status or stigmatize the group in which an individual belongs.¹⁹

A multicity survey of the general population found that women were more likely than men to believe that women research participants are at greater risk than men are of being "taken advantage of" in research studies. A large portion of survey respondents, particularly black respondents, cited historical events as contributing to their beliefs about the vulnerability of women as biomedical research subjects. More than half the respondents believed that women of childbearing age should not participate in clinical research.²⁰

Several studies reported that African-American women were more likely than white women to report distrust of the medical system and negative attitudes about clinical trials.^{21 22} Another study on breast cancer found that non-white women were more likely than white women to report concerns about experimentation. The study authors concluded that reasons for refusal to participate can differ by subgroup; consequently, the researchers planned to address those barriers.²³

Mistrust is also a factor in recruiting rural women; however, recruitment of rural women can be even more burdensome because of additional difficulties, such as transportation issues.^{24 25} Although minority populations express greater mistrust of research, they are not necessarily less willing than white populations to participate in research once these barriers are addressed.²⁶

3. Lack of knowledge and understanding of the clinical process

Researchers have identified a lack of knowledge and understanding among the general public about the importance or role of clinical research. In a study of Chinese-American women cancer patients, investigators found that 62 percent lacked any knowledge of clinical trials and many expressed negative attitudes toward them.²⁷ In a qualitative study measuring the willingness to participate in breast cancer trials, Latinas did not recognize breast cancer as affecting their community, which partially explained the low participation in these trials. This study identified the need to educate women on the importance of participating in clinical trials.²⁸

Another significant issue is lack of knowledge among people about informed consent procedures and protections. A finding from a study involving pregnant women adds to the growing body of evidence that a gap exists between participants' understanding and researchers' perception of that understanding. The nature of the study or the situational context can affect a participant's ability to fully absorb information.²⁹

In other cases, however, knowledge is not necessarily a barrier to participation. Avis and colleagues found that the level of knowledge about breast cancer treatment trials was not associated with women's willingness to participate. The women who declined to participate cited the amount of time

and travel, potential adverse effects, and concerns about random assignment as the biggest factors preventing their own participation.³⁰

Securing informed consent and ensuring understanding are essential in clinical trials. Issues of autonomy are paramount in an individual's decision to participate in a study, but sometimes language can also limit a participant's ability to fully understand the research materials. Asian women and their oncologists identified language as a barrier to participation. Oncologists also said that a dearth of culturally relevant^a cancer information exists.³¹ Lack of translated materials, feeling intimidated by the English language, and lack of translation of key words or terms were among the reasons that Asian-American women at risk for cervical cancer refused to participate in research.³² Researchers identified language as affecting study recruitment³³ and reported difficulty in obtaining interpreters and lack of sufficient bilingual staff that could recruit potential participants who spoke only Spanish.³⁴ Chinese-American women were more likely to participate in a clinical trial when a trusted oncologist or another trusted individual recommended that the women participate and provided information about the trial in the women's primary language.³⁵

4. Fear of risk and randomization

Patients who are asked to participate in research may refuse, fearing adverse effects on their health^{36 37 38} or loss of control in making their own decisions regarding their health.³⁹ In some cases, patients feared that they would be randomized into a control group and would not receive the desired medical intervention.^{40 41} Acceptance of randomization was the strongest predictor of whether a woman with breast cancer would be willing to participate in a hypothetical clinical trial.⁴² A systematic review of breast cancer studies concluded that randomization can influence participation rates and cited several articles that identified randomization as a reason for declining participation.⁴³ A review of randomized trials for the treatment of symptomatic uterine leiomyoma found that randomization to placebo adversely affected recruitment.⁴⁴ A study of outpatient gynecology patients with symptomatic prolapse found that one barrier to recruitment included the patients' preference to receive active treatment rather than be allocated to the control group.⁴⁵

In other cases, prospective participants feared that participating in the study could result in negative health consequences. Schonfeld and colleagues found that a study



^a Culturally relevant health care and health care research mean “understanding, valuing, and incorporating the cultural differences of America’s diverse population and examining one’s own health-related values and beliefs, [so that] health care organizations, practitioners, and others can support a health care system that responds appropriately to, and directly serves the unique needs of populations whose cultures may be different from the prevailing culture.” Adapted from the U. S. Department of Health and Human Services, Office of Public Health Sciences (OPHS), Office of Minority Health. (2001, March). [National Standards for Culturally and Linguistically Appropriate Services in Health Care. Final Report](#), p 4.

design in which women were randomized to one of three contraceptive methods affected the women's perceived risk. As a woman's perception of risk increased, her willingness to participate in the study decreased.⁴⁶

Participants raised other fears in addition to risk to their physical health. A cancer prevention study involving older Filipino Americans found that women may refuse to participate out of fear that it could negatively affect their immigration status or their Social Security benefits. Researchers also found that having to sign an informed consent form was an important barrier to participation for women whose primary language was not English.⁴⁷

Fear of stigma can also play a role in some studies, such as those focusing on HIV research. In one study, most of the participants reported feeling shame and stigma related to their HIV-positive status.⁴⁸ HIV-positive women in another study identified HIV disclosure, stigma, and fear as barriers to participating. The sensitivity of the research topic was also mentioned as a significant barrier.⁴⁹

Facilitators

No simple solution exists to the challenge of recruiting and retaining women in clinical research. What emerged in the literature is that investigators need to implement a range of strategies that align with the needs and concerns of the target population. This means that successful recruitment begins with learning about the study population and what barriers will most likely be issues for members of that population. The facilitators presented in this section essentially address the barriers most often cited in the literature—that is, barriers related to study burden, distrust of the medical community, lack of knowledge, and fears associated with clinical research. By using effective implementation techniques when incorporating these facilitators, investigators could identify strategies to address and resolve multiple barriers to study recruitment and participation.

1. Providing compensation

Poverty can be a major barrier to research participation for women and men alike. Many low-income women cannot



afford any financial costs associated with study participation, such as transportation. Cultural sensitivity,^b which includes awareness of social and economic barriers to participation, is essential.⁵⁰ Simple monetary incentives may not be sufficient, but a number of studies have found that monetary incentives can help with recruitment and retention.^{51 52 53} Women viewed incentives as a benefit and did not perceive them as coercive⁵⁴ but rather as compensation for their time.⁵⁵ Providing periodic financial incentives, including cash, gift cards, and gifts commensurate with participants' efforts, were identified as important strategies to retain women in longitudinal studies.⁵⁶

In addition to financial incentives, studies also included other types of incentives, such as reimbursing participants for out-of-pocket expenses related to transportation or, sometimes, child care.^{57 58} A large-scale cervical cancer screening trial provided incentives, reimbursed participants for travel and child care expenses, and provided free oral contraceptives.⁵⁹ Strategies to recruit older women to surgical trials included

^b Cultural sensitivity is "the ability to be appropriately responsive to the attitudes, feelings, or circumstances of groups of people that share a common and distinctive racial, national, religious, linguistic or cultural heritage." Source: U. S. Department of Health and Human Services, OPHS, Office of Minority Health. (2001, March). [National Standards for Culturally and Linguistically Appropriate Services in Health Care. Final Report.](#) Glossary, p. 131.

scheduling study visits around transportation availability and providing compensation for travel expenses.⁶⁰

2. Being flexible and accommodating in research visits

Researchers can address a number of barriers related to study burden by being flexible and accommodating when possible. For example, being flexible in scheduling study visits or location can make it easier for people to participate.⁶¹⁶²⁶³⁶⁴ To address barriers, one study limited interviews to 15 minutes, conducted them by telephone, and scheduled interviews during the evenings and weekends, which enabled study participants to engage in the process more easily and to avoid having to access transportation.⁶⁵ Another study also prioritized convenience and suggested ensuring a wide variety of times and modalities for the intervention and offering home-based study assessments when possible.⁶⁶

Recruiting and retaining efforts need to be tailored to meet the needs of the target population. Investigators working with Latina mothers and their infants advised budgeting for the cost of taxicabs, providing a child-friendly research site for the mothers' other children, and allowing flexibility with the appointment times.⁶⁷ Subject retention for a physical activity intervention with African-American women was high, possibly because of flexible scheduling, frequent contact, and a caring environment.⁶⁸ Rural Hawaiian women appreciated the flexibility in data collection (at church and by phone) and in follow-up for missing and incomplete surveys.⁶⁹

3. Communicate clearly

The importance of clear communication cannot be overstated and, when effective, can improve participant knowledge and address issues of mistrust and fears that potential participants might have. The [NIH Clear Communication Initiative](#) stresses the use of plain language and providing culturally competent^c content in a form that is accessible to target audiences. Study participants mentioned the importance of materials that were written in easy-to-understand language and presented information clearly.⁷⁰

The clinician's ability to effectively communicate the value of

the trial, describe the benefits and side effects, and address patient concerns was considered important by participants.⁷¹⁷² Good communication among the investigators, providers, and participants had a positive impact on recruitment.⁷³ The literature also indicates that potential methods to increase accrual include explaining both the rationale of the study and the need for randomization.⁷⁴ The recruitment process allows investigators to fully inform participants about the study purpose and, if randomization is used, why it is important. Women who accepted randomization were inclined to follow their doctors' recommendations, which suggests that doctors should discuss the benefit of clinical trials and the need for randomization with their patients so that they can make informed decisions about study participation.⁷⁵ Potential methods to increase accrual include ensuring that patients receive adequate information about the study's purpose, available treatment options, and the randomization process.⁷⁶

Describing different aspects of participation, including the potential risks, is particularly important for subgroups, such as minority women, for whom the issue of trust may be of particular concern. To recruit more minority women to clinical trials, investigators must explain to the women what clinical trials are, how they are designed and implemented, and the informed consent process.⁷⁷ Providing this information is also important for pregnant women or women who are likely to become pregnant. Women of childbearing potential must understand the requirements of the study and decide whether it is appropriate for them to participate (i.e., whether the benefits outweigh the risks). Even with institutional review board approval, the research team must make special efforts to ensure that women who are considering participation fully understand the demands of the study and what participants will be asked to do.

4. Establish good relationships

Several studies reported that developing a connection with study participants helped with recruitment efforts and long-term retention. The researchers' demeanor, communication skills, and treatment of participants are all factors in developing good relationships with the

^c "Culture refers to integrated patterns of human behavior that include the language, thoughts, communications, actions, customs, beliefs, values, and institutions of racial, ethnic, religious, or social groups. Competence implies having the capacity to function effectively as an individual and an organization within the context of the cultural beliefs, behaviors, and needs presented by consumers and their communities." Source: U. S. Department of Health and Human Services, OPHS, Office of Minority Health. (2001, March). [National Standards for Culturally and Linguistically Appropriate Services in Health Care. Final Report](#). Glossary, p. 131.

study subjects. For example, participants in an HIV study stated that an important recruitment factor was research personnel who were respectful, experienced, flexible, and empathetic and had good community skills.⁷⁸ Several studies identified the ability of the researchers to develop positive relationships with the study participants as helpful. Allowing for opportunities in which researchers could engage with participants could go a long way to building rapport, increasing participants' comfort in the research environment, and addressing participants' distrust of the medical community.⁷⁹ One study used the Heiney-Adams Recruitment Framework, which is designed to build trusting relationships with study participants through the use of social media.⁸⁰ Investigators tried to establish warm personal bonds with participants, which has important cultural value^d in the Latino population, by maintaining regular contact and holding parties for special occasions.⁸¹

Developing strong relationships early in the study also can be a retention strategy. In a study of rural women with cancer, the retention strategies that worked were maintaining contact with the participants and having a research nurse who provided support and developed caring relationships with the participants.⁸² A review of the literature of clinical leiomyoma trials suggests that multiple strategies are needed to recruit clinical trial participants in sufficient numbers and of sufficient diversity. The review found that developing trusting relationships between study personnel and patients and maintaining continued contact and conducting follow-up with participants can increase retention.⁸³ A trusting and caring relationship between research nurses and participants was a major factor in patient accrual and retention in a behavioral trial involving diabetic women with depression. During telephone recruitment, nurses made an effort to understand the patients' needs and build trust. The nurses provided the patients with a caring environment during the baseline visit and kept in touch with them to continue building and maintaining their trust.⁸⁴

5. Maintain consistent contact

Part of developing good relationships with study participants involves maintaining frequent communication, which strengthens relationships over time. Consistent contact with

study participants also helps in keeping contact information up to date.⁸⁵ One study reported developing a database to help the study team track participants in danger of attrition.⁸⁶ Another study that recruited older rural minority women found that providing a toll-free number and a consistent person for follow-up visits were effective practices.⁸⁷ Studies used a range of strategies to keep in touch with participants, including the following:

- Phone calls and texting^{88 89 90 91 92 93 94}
- Email and social media^{95 96 97}
- Letters, birthdays and holiday cards, and other mailings^{98 99 100 101 102}
- Parties and special events¹⁰³

The most commonly reported investigator contact with participants after recruitment was through phone calls, text messages, or emails reminding participants about an upcoming research visit. For a large-scale cervical cancer screening project, participants received a study newsletter every few months, birthday and holiday cards, and reminder calls before a study visit.¹⁰⁴ An observational study of predictors of heart disease used a variety of strategies to retain participants, including telephoning those who missed an appointment and sending a "missing you" letter to those who could not be contacted. The letter was effective in contacting the women, who then completed their interviews. Investigators also were often able to obtain new addresses when a "missing you" letter was returned.¹⁰⁵

Maintaining periodic contact with participants appeared to be more effective than communicating with them only around study visits. For example, a study involving African-American breast cancer survivors found that periodically sending participants appreciation letters and small financial incentives and initiating telephone contact with participants at risk of dropping out were effective in retaining participants.¹⁰⁶ In another research study, successful retention efforts included making phone calls every other month and sending birthday cards to parents and children, both of which helped foster feelings of connection to the study.¹⁰⁷

^d A cultural value is a commonly held standard "of what is acceptable or unacceptable, important or unimportant, right or wrong, workable or unworkable, etc., in a community or society." Definition from BusinessDictionary.com.

6. Address cultural competence

Incorporating cultural sensitivity and competence in recruitment efforts was recommended when working with minority or immigrant populations. According to the NIH Clear Communication Initiative:

Culture is often described as the combination of a body of knowledge, a body of belief and a body of behavior. It involves a number of elements, including personal identification, language, thoughts, communications, actions, customs, beliefs, values, and institutions that are often specific to ethnic, racial, religious, geographic, or social groups. For the provider of health information or health care, these elements influence beliefs and belief systems surrounding health, healing, wellness, illness, disease, and delivery of health services. The concept of cultural competency has a positive effect on patient care delivery by enabling providers to deliver services that are respectful of and responsive to the health beliefs, practices, and cultural and linguistic needs of diverse patients.

George and colleagues suggested that research staff could help overcome potential participants' distrust and lack of knowledge of clinical trials by conducting an open discussion and providing opportunities for participants to ask questions. Consent forms should also address participants' concerns

and be developed with input from the community.¹⁰⁸ One study suggested including a Certificate of Confidentiality as part of the standard protocol during the consent process to reassure immigrants participating in research that their immigration status would remain confidential.¹⁰⁹



The cultural background of the study population can affect the recruitment approach and messaging in recruitment materials. For example, one study found that when recruiting Latinas, the research methods should focus more on family involvement because of the importance of family in the Latino community.¹¹⁰ In another study recruiting Chinese Americans, culturally relevant recruitment strategies included face-to-face enrollment and the use of bilingual and bicultural staff. Most of the study's participants were recruited face to face in a community setting, such as at Chinese schools, stores, and health fairs and through personal networks.¹¹¹

Several studies referenced the value of developing culturally appropriate^e materials, such as posters, flyers, logos, intervention materials, and messages for minority populations.^{112 113} Using linguistically appropriate materials

^e Culturally appropriate in the realm of health care and medical research refers to health care services, practices, or materials that "are respectful of and responsive to the health beliefs, practices, and needs of diverse patients." Source: Office of Minority Health, [U.S. Department of Health and Human Services](#), (n.d.). [Think Cultural Health website](#).

was crucial for successfully recruiting a large number of Chinese Americans in community and clinical settings.¹¹⁴ Investigators successfully recruited pregnant Hispanic women by using culturally and linguistically appropriate recruitment strategies, including bilingual recruiters, flexible recruitment, and culturally tailored materials.¹¹⁵ A study recruiting African-American and Hispanic women revised its materials to make them more culturally relevant. Investigators modified the National Cancer Institute's Clinical Trials Education Series by introducing a sisterhood theme and including photos of women from diverse backgrounds.¹¹⁶

7. Diversify staff and the study team

One strategy to address cultural competence is to include investigators and staff who reflect the study population and may better understand and connect with a population's behaviors, language, customs, and beliefs. The use of culturally linked and bilingual interviewers was one of the most effective recruitment methods.^{117 118} For example, in one study, hiring culturally appropriate data collectors by recruiting Arab Muslim mothers—in addition to having one of the members of the study population serve as an investigator—was effective, because the study staff were able to establish culturally appropriate connections with the study participants.¹¹⁹

In a study that included Hispanic women, sensitivity and cultural competence were enhanced by the principal investigator's expert knowledge of Hispanic culture. Investigators took steps to incorporate cultural sensitivity and competence into their efforts to recruit pregnant women living on the U.S.-Mexico border.¹²⁰ Another study involving Filipino Americans found that a personal invitation for study participation from either a female project liaison or the Filipino project director was a successful engagement strategy.¹²¹

8. Engage community members and organizations

Effective outreach to women and specifically minority women, especially those who are difficult to access, must incorporate a partnership approach involving participation by potential research subjects, investigators, community-based organizations, and other relevant stakeholders in the research process. Engaging community members in the research activities was pivotal in meeting the recruitment and enrollment goals and in resolving key barriers that well-trained researchers were previously unable to address.¹²²

Several studies found that engaging community members or a community advisory board was helpful in building prospective participants' trust^{123 124 125 126} and informing the recruitment strategies.^{127 128} Several studies used a community-based participatory model to guide research activities in site identification, recruitment, and materials development. One study engaged community representatives and promotoras, whereas another study formed community advisory committees and community leaders.^{129 130}

Working with community gatekeepers, such as church and civic leaders and community health care professionals, to develop trust within a community is important to recruitment.¹³¹ Several studies described working with cultural experts or consultants who served as study advisors and were helpful in identifying community gatekeepers, study sites, and data collectors.^{132 133} Researchers who conducted a diabetes study in New York City stated that engaging community leaders as champions and recruiters served as the most successful recruitment approach, because these community partners engendered trust among participants.¹³⁴

Engaging key organizations, like churches, could inform potential participants and connect researchers with study populations. African-American women cancer survivors taking part in focus groups reported that African-American churches are a good place to educate the community about clinical trials. Using respected members of the community, particularly those who have participated in a clinical trial, could help in recruitment efforts.¹³⁵ A feasibility study of a breast cancer screening intervention with rural Hawaiian women found that recruitment through rural churches exceeded recruitment targets and that retention rates were comparable to other clinical trials. The study confirmed that outreach to rural Hawaiian women through their churches is an effective strategy.¹³⁶

Community engagement is essential to the development of an effective plan to improve recruitment of underrepresented groups in clinical trials. For example, in recruiting women at risk for HIV, engaging community partnerships was a critical element to help build trust and identify study communities and venues.¹³⁷ Studies found that partnering with community organizations and recruiting minority women through churches and community events were more effective than mailings¹³⁸ or other recruitment strategies.¹³⁹ Investigators working with Chinese-American



women reported that recruitment through personal, language-appropriate invitations at community-based locations can create a participant pool that could be used in subsequent trials.¹⁴⁰ Working with community-based partners also worked well with rural and other hard-to-reach populations.¹⁴¹ A study that reviewed the literature on retention of abused women in longitudinal studies found that partnering with agencies was an important strategy to identify and approach potential participants.¹⁴²

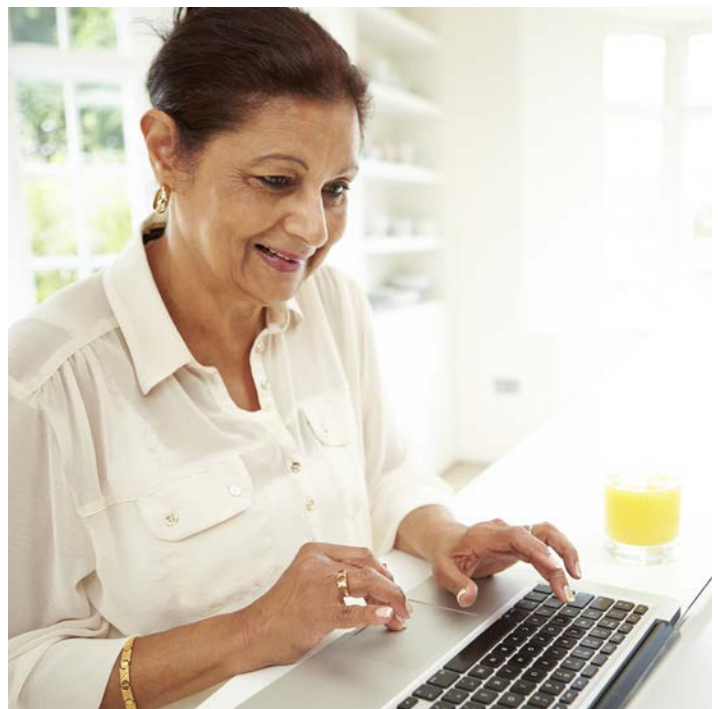
9. Implement marketing strategies

Marketing approaches were helpful in expanding reach for recruitment efforts and involved the use of posters, flyers, and advertisements through newspapers, television, and radio. Studies reported different levels of success with different strategies and typically used multiple marketing approaches. The use of posters, flyers, and direct mailings were the most effective methods, although multiple methods were necessary to reach accrual goals.^{143 144}

In some cases, a study would implement marketing approaches after in-person efforts did not yield accrual

targets. One study had planned to recruit postmenopausal women through physical recruiters but, due to under-enrollment, turned to newspaper advertisements, which proved to be very successful.¹⁴⁵ Placing newspaper ads yielded the most inquiries for some studies¹⁴⁶ or was very effective when combined with other efforts, such as direct mailings.^{147 148} In a study on chemical exposure in pregnant women, the researchers found that posters and flyers at hospitals and clinics, targeted trade shows, and online advertising generated the most inquiries about the study and served as the most successful recruitment strategies.¹⁴⁹ Implementing these approaches by using newspaper ads and targeted mailings was also more cost-effective.

Another study reported having more recruitment success through more costly strategies, including the use of television, radio, and the Internet.¹⁵⁰ Several studies also used the Internet and social media platforms to recruit younger women and adolescents.^{151 152} Notice boards on Facebook and Twitter yielded the highest recruitment numbers in the shortest timeframe for one study.¹⁵³ Another study also successfully recruited young women using a Facebook-targeted advertising system, which was cost-effective.¹⁵⁴



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