

Case Study: Arizona Cervical Cancer Prevention Unit



Principal Investigator

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Project

Between 2000 and 2012, the Arizona Cervical Cancer Prevention Unit conducted a series of clinical trials in the area of women's cancer prevention, focusing primarily on cervical cancer. The series included trials on drugs, molecular marker discovery, community intervention, and technology assessment. Some trials were funded by the federal government, and some were funded by private companies.

Target Population

The trials enrolled women of reproductive age and in midlife who lived in southern Arizona. The research team sought representation of Hispanic women and low-income women in the study groups.

Recruitment Approach

- The researchers began building relationships within the community years before the trials started. They connected with health care providers, community centers, libraries, social organizations, and faith-based groups.
- Through various processes with the stakeholders, the researchers identified cervical cancer prevention as a health priority in the community.
- The researchers compiled educational resources on cervical cancer for dissemination at libraries, schools, and other locations.

- The community ultimately viewed the research unit's investigators as trustworthy, knowledgeable, and useful resources in the area of women's cancer prevention. Consequently, the study recruitment process was relatively easy.
- When trials started, the researchers contacted the stakeholders and informed them about the kinds of patients that were needed for the trials and how interested parties could get in touch with the researchers. The trials enrolled several thousand women.

Primary Barriers

- Many of the women in the target population had economic challenges that made it difficult for them to take the time to participate in a trial.
- In addition, many of the women had limited formal education and were unfamiliar with the science involved in clinical trials and the process of medical research.
- Building trust within the community was expensive and took time and funding.



Successful Recruitment Strategies

- The team employed linguistically and culturally competent staff members who conducted the outreach, education, and consent process for the trials. Consequently, women who were considering enrolling in the trials received answers to their questions immediately, from a person who not only spoke their language but also understood their cultural background.
- The researchers devoted much energy into developing a consent process that was meaningful to women who were considering joining the trials. The researchers had to translate mandatory consent language, interpret the material culturally, and present it in such a way that potential participants could understand it.
- The chemoprevention trials required all participants to use contraception. Since a large percentage of the target population was uninsured and could not always afford to purchase contraception, receiving it for free was an incentive to join the trials.
- Since the passage of the Patient Protection and Affordable Care Act in 2010, the percentage of people without insurance in the region has dropped and the availability of contraception has become less of an incentive to participate in trials.



Retention Strategies

- The research staff developed good relationships with the participants. This was particularly important in chemoprevention trials, because the women had to participate on a long-term basis.
- The research staff members were available to the participants by telephone, text, or any other participant-preferred communication method.
- One of the advantages of participating in the study was the resulting connection with a health care resource. When needed, study staff connected the women with health care systems or provided health care directly.

Lessons Learned

- The researchers found that relationships with institutions and organizations in the community were extremely important, especially for recruiting patients of low socioeconomic status. The researchers needed to be viewed not as people who were visiting the community only to conduct clinical trials but as positive players within the community who were available before, during, and after the research. The Arizona Cervical Cancer Prevention Unit successfully fostered that image in the community, which helped make the research successful.
- Maintaining the relationships with the community members would have been helpful, for example, by contacting individual study participants and providing them with an individualized understanding of the study findings.

