

## **Choice to Join a Breast Cancer Registry: Racial Differences**

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**Background:** Cancer registries are an important resource for epidemiology studies. Unlike state or federal registries, cancer registries created for support of research rely on voluntary participation, but are especially important for studies of environmental or lifestyle risk factors and genetic susceptibility. What are the best strategies for registry recruitment, measured either by ascertainment of a representative set of cases or by cost- and effort-effectiveness?

**Objectives and Methods:** We have used the infrastructure of the Breast Cancer Registry of Greater Cincinnati to study the effectiveness and efficiency of various recruitment strategies. Our research questions are: What method 1) yields the best enrollment return rate; 2) is most successful in enrolling those usually under-represented in medical research; and 3) is most cost effective? We conducted a retrospective data analysis of information on 3000 persons in the Registry database, who enrolled from May 11, 2004 until September 30, 2005, to determine if their demographic and clinical characteristics differ by the method of recruitment that resulted in their enrollment. Additionally, using data on the community-wide distribution of approximately 8000 Registry enrollment forms over that same time period, logs of personnel effort hours spent on recruitment activities, and costs of materials and postage, we have calculated the efficiency (enrollment yield vs. cost and time burden, or “return on investment”) of different recruitment methods. We also have ascertained which recruitment methods are most effective in enrolling those traditionally difficult to recruit for research studies, notably African-Americans, but also other groups with low enrollment rates.

**Results:** Preliminary data analyses suggest distributing recruitment packets through physicians’ offices yields the best return in number of enrollees at the lowest cost. However, we are not able to discern if a survivor who has previously received information about the Registry through outreach events may be more likely to enroll when she later receives the packet from her physician’s office.

**Conclusions:** Population based registries are costly. Little information is known about the best strategies to use in recruiting for these voluntary registries and the most efficient settings and strategies for recruitment. Data driven choices for recruitment methods may reduce costs.

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