

Innovative Utilization of a State Cancer Registry to Contact Young Breast Cancer Survivors and their

High-Risk Female Relatives to Increase Breast Cancer Screening

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BACKGROUND

- Young breast cancer survivors (YBCS) and their first- and second-degree relatives are at increased risk for cancer
- Breast cancer diagnosed at a young age indicates a possible hereditary cause
- Because of this increased risk, genetic counseling, earlier screening and prevention services are recommended for these high-risk women

PURPOSE OF STUDY

To examine the feasibility of using a statewide cancer registry to recruit YBCS and their high-risk female relatives in a randomized efficacy trial aiming to increase cancer screening and use of genetic services

METHODS

- In collaboration, the University of Michigan School of Nursing and the Michigan Department of Community Health developed and piloted a “cascade” recruitment method for high-risk families using the Michigan Cancer Surveillance Program (MCSP)
- A random sample of **3,000 YBCS** (diagnosed between 20-45 years old), stratified by race (1,500 black and 1,500 white/other races) in the years 1994-2008 were identified.
- The diagnosing facility and physician were contacted to determine reasons to not contact the YBCS
- YBCS was enrolled if she was eligible, signed an informed consent and completed a baseline survey

YBCS ELIGIBILITY CRITERIA

Female, 20 years or older, able to read English
Michigan resident at time of diagnosis
Diagnosed with invasive breast cancer or DCIS between 20-45 years
Not currently pregnant, incarcerated, or institutionalized

METHODS

- Enrolled YBCS reported in the baseline survey first- and second-degree female relatives, with no history of cancer, who were willing to invite in the study
- Genetic counselors reviewed the information and selected up to two relatives per YBCS

RELATIVE ELIGIBILITY CRITERIA

YBCS is willing to contact
Female, 25-64 years of age, able to read English, US resident
Unaffected with any type of cancer
First- or second-degree relative of the YBCS
Not currently pregnant, incarcerated, or institutionalized

- YBCS were notified of the selected relatives and were asked to contact them for study participation
- Relatives were enrolled once they returned a signed informed consent and a completed baseline survey

RESULTS – RECRUITMENT OF YBCS (FIGURE 1)

- 883 YBCS accepted participation in the study (33.2% response rate)
- Most common reason for not taking part was no known address for YBCS
- Black YBCS had a higher percentage of bad addresses than Whites/Other
- 281 YBCS had no eligible relatives

RESULTS – RECRUITMENT OF RELATIVES (FIGURE 2)

- Genetic counselors identified 1,875 eligible first- and second-degree female relatives
- YBCS were willing to contact 1,360 relatives
- Recruitment materials were provided to 522 YBCS to distribute to 856 relatives
- 442 relatives who accepted participation in the study (51.6% response rate)
- 185 family units that included the YBCS with 1 relatives and 123 family units that included the YBCS with 2 relatives

FIGURE 1. YBCS RECRUITMENT FLOW CHART

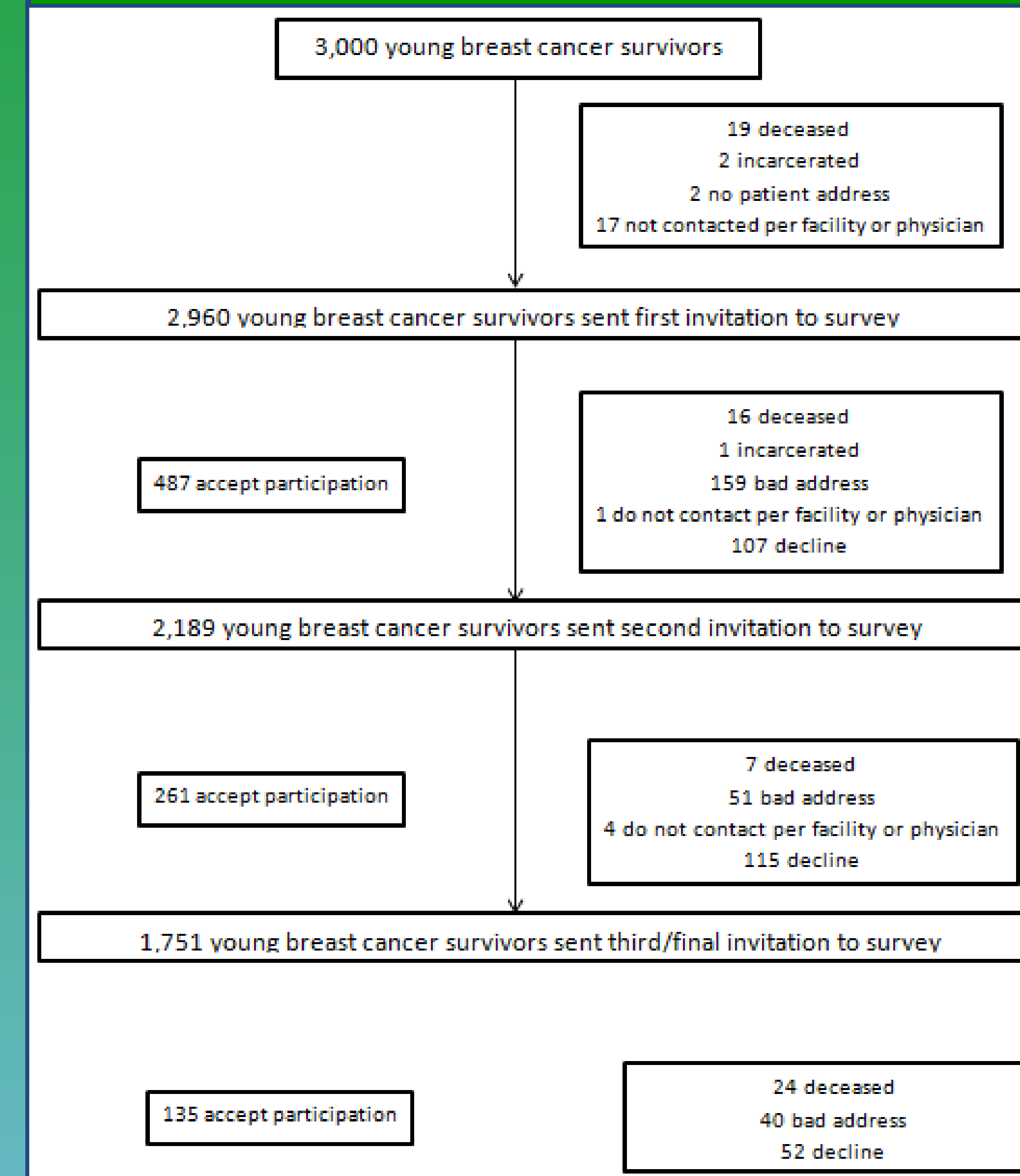
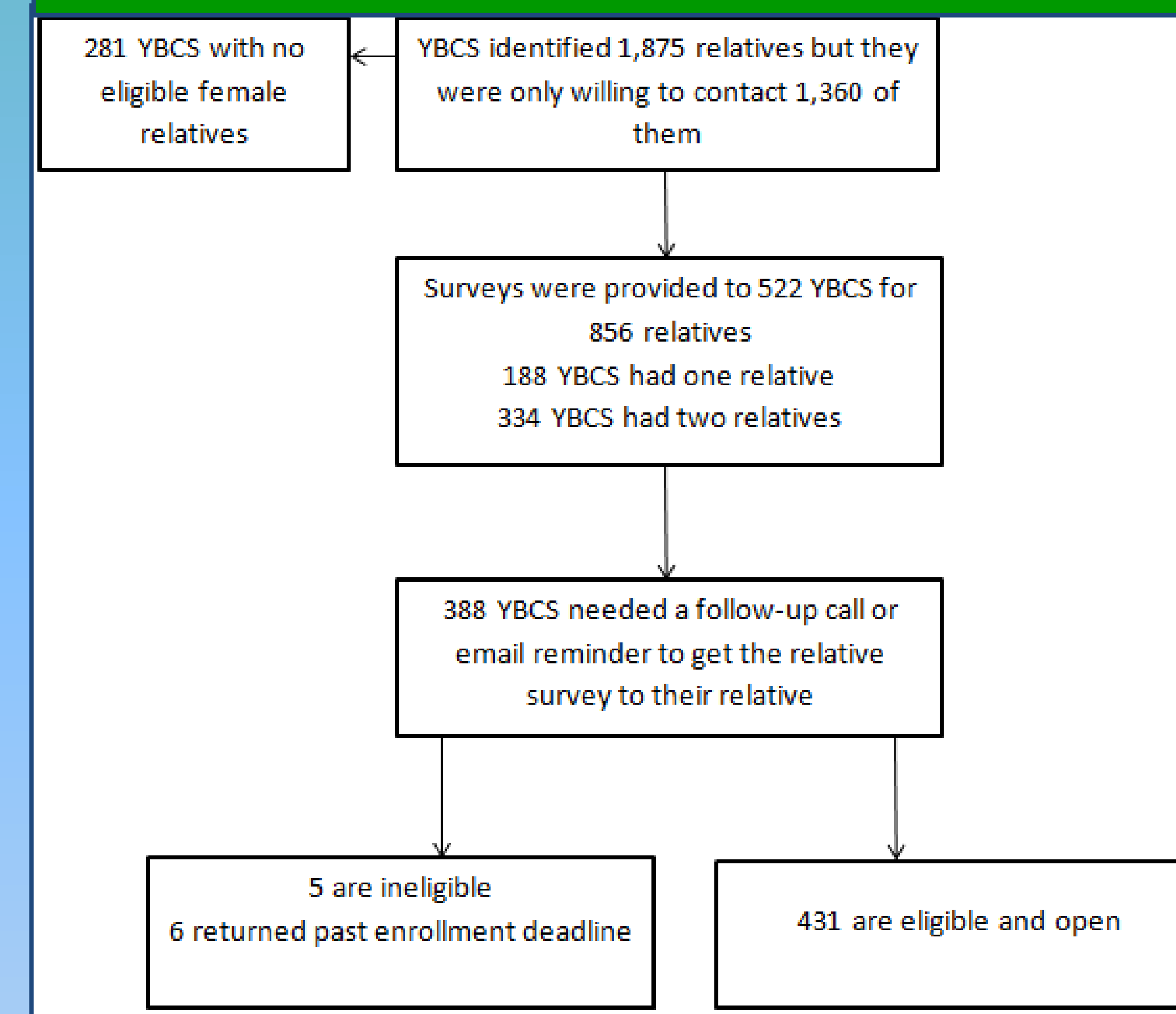


FIGURE 2. RELATIVE RECRUITMENT FLOW CHART



RESULTS – DEMOGRAPHICS

(TABLE 1)

- YBCS were on average 51 ± 6 years old and relatives were 43 ± 12 years old
- Fewer Black YBCS and relatives accepted participation in the study
- Enrolled Black YBCS and relatives were significantly less likely to be married, have insurance coverage, and less education and income compared to White/Other YBCS and relatives
- Enrolled family units were randomized and received one of two versions of printed materials
- Approximately 9 months post-intervention family units were mailed a follow-up survey
- To date, a total of 594 YBCS (74.7%) and 341 relatives (79.3%) have returned a follow-up survey

TABLE 1. DEMOGRAPHICS OF THE YBCS AND THEIR HIGH-RISK RELATIVES

	YBCS			Relatives		
	Total	Black	White/Other	Total	Black	White/Other
Average Age (yrs)	51 ± 6	51 ± 6	51 ± 6	43 ± 12	45 ± 11	43 ± 12
Time since Diagnosis (yrs)	11 ± 4	11 ± 4	11 ± 4	n/a	n/a	n/a
White/Other	60.4%	8.9%	100%	79.8%	10.3%	100%
Black	39.6%	100%	0.0%	20.2%	100%	0.0%
Married*	57.1%	33.1%	72.7%	55.6%	33.3%	61.2%
High school grad or less*	23.4%	30.4%	18.9%	17.0%	28.0%	14.3%
Household income <\$60,000*	52.8%	65.4%	34.3%	52.6%	69.7%	43.6%
Has medical insurance*	93.5%	90.6%	95.4%	87.0%	75.9%	89.8%

CONCLUSIONS

- The enrollment and follow-up response rates indicate that using a state cancer registry to reach cancer survivors and high-risk relatives is a feasible recruitment method
- Using a state cancer registry allows for increased outreach to a unique population that has high cancer risk and needs increased cancer surveillance and screening
- The study took an innovative approach to using family health history and is suggested as a method of recruitment for cancer survivors and relatives

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