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# Race/ethnicity and accuracy of self-reported female first-degree family history of breast and other cancers in the Northern California Breast Cancer Family Registry

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## Abstract

**Background:** Few studies have evaluated accuracy of self-reported family history of breast and other cancers in racial/ethnic minorities.

**Methods:** We assessed the accuracy of cancer family history reports by women with breast cancer (probands) from the Northern California Breast Cancer Family Registry compared to two reference standards: personal cancer history reports by female first-degree relatives and California Cancer Registry records.

**Results:** Probands reported breast cancer in first-degree relatives with high accuracy, but accuracy was lower for other cancers. Sensitivity (% correctly identifying relatives with cancer) was 93% (95% CI, 89.5–95.4) when compared to the relatives' self-report of breast cancer as the reference standard and varied little by proband race/ethnicity and other demographic factors, except for marginally lower sensitivity for Hispanic white probands (87.3%, 95% CI, 78.0–93.1, $P$=0.07) than non-Hispanic white probands (95.1%, 95% CI=88.9–98.0). Accuracy was also high when compared to cancer registry records as the reference standard, with a sensitivity of 95.5%

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EMJ acquired the data, conceived of and designed the analysis, interpreted the data, and drafted and revised the manuscript. AC and JK performed data management and the statistical analysis, interpreted the data, and participated in the revision of the manuscript. MS contributed to the literature review and writing, interpreted the data, and participated in the revision of the manuscript. ASW and DWW acquired the data, interpreted the data, and participated in the revision of the manuscript. All authors approved the manuscript being submitted.

Conflict of interest:

The authors declare they have no conflicts of interest.

(95% CI, 93.4–96.9) for breast cancer, but lower sensitivity for Hispanic white probands (91.2%, 95% CI, 84.4–95.2, $P$=0.05) and probands with low English language proficiency (80%, 95% CI, 52.8–93.5, $P$ <0.01).

**Conclusions:** Non-Hispanic white, African American, and Asian American probands reported first-degree breast cancer family history with high accuracy, although sensitivity was lower for Hispanic white probands and those with low English language proficiency.

**Impact:** Self-reported family history of breast cancer in first-degree relatives is highly accurate and can be used as a reliable standard when other validation methods are not available.

### Keywords

Accuracy; African Americans; Asian Americans; breast cancer; cancer family history; epidemiology; Hispanics; Latinas

## Introduction

Family history is a well-established risk factor for breast cancer, with two- to four-fold increased risks depending on the number of affected relatives and their ages at diagnosis (1,2). Prevalence estimates from population-based studies range from 8–18% for first- and second-degree family history of breast cancer (3,4). Family history is an important component of risk assessment and may guide screening such as age at screening initiation, frequency of screening, or method of screening, preventive interventions such as chemoprevention or risk reducing surgeries, or referral for genetic counseling and testing. Family history assessment usually relies on self-report. Reporting accuracy is generally high for both personal history (5–8) and first-degree family history (9–12), but lower for second- and higher-degree family history of breast cancer (9–11) and for other cancers (9,11,13,14).

Data on racial/ethnic differences in accuracy of reported family history of breast cancer are sparse (10,15). The prevalence of first-degree family history of breast cancer reported by minority populations has been shown to be lower compared with non-Hispanic white populations (3,4,11,16–21). Such differences may reflect true racial/ethnic differences in breast cancer incidence, or differences in the accuracy of family history reporting associated with differences in sociodemographic characteristics (e.g., age, education, and income), knowledge and communication about cancer among family members, or cultural and generational barriers to discussing cancer in the family.

We examined the accuracy of first-degree family history of breast and other cancers reported by African American, Asian American, Hispanic white, and non-Hispanic white women with breast cancer enrolled in the Northern California Breast Cancer Family Registry (NC-BCFR) (22,23).

## Materials and Methods

### Study population

NC-BCFR enrolled nearly 3,700 population-based breast cancer families of whom 75% are racial/ethnic minorities (22). The Institutional Review Boards of the Cancer Prevention

Institute of California and Stanford University approved the study and participants provided written informed consent. Details on the study design are provided elsewhere (22). Briefly, a total of 34,517 women ages 18–64 years newly diagnosed with breast cancer were ascertained through the Greater San Francisco Bay Area Cancer Registry (diagnoses 1995–2009) and the Sacramento and Sierra Cancer Registries (diagnoses 2005–2006), which are part of the California Cancer Registry (Figure 1). Study eligibility was assessed by a telephone screening interview (85% participation) that assessed self-reported race/ethnicity and personal and family history of breast, ovarian, and childhood cancers. All cases with any indicators of hereditary breast cancer (i.e., diagnosed before age 35 years; personal history of ovarian or childhood cancer; bilateral breast cancer with a first diagnosis before age 50 years; a first-degree family history of breast, ovarian or childhood cancer) were invited to enroll in the NC-BCFR. Cases not meeting these criteria were randomly sampled (2.5% of non-Hispanic whites and 50% of others). Of 4,841 women with breast cancer selected for NC-BCFR, 3,671 (76%) enrolled as probands and completed the baseline family history and risk factor questionnaires. After excluding 51 secondary and tertiary probands from multiple-proband families, five probands for whom a proxy respondent completed the questionnaires, and two probands with incomplete risk factor questionnaires, cancer family history reports by 3,613 probands were available for analysis. Of these, 1,947 (53.9%) had one or more of the above mentioned indicators of hereditary breast cancer.

Only adult family members were enrolled in NC-BCFR; therefore, the enumeration of relatives was limited to those ages ≥18 years. The 3,613 probands enumerated 13,906 female first-degree relatives (mothers, full and half-sisters, and daughters), of whom 4,375 were alive, lived in North America, had the proband's permission to be contacted, and for adult daughters only, had a history of breast cancer. Of these, 3,384 (77%) enrolled in NC-BCFR and completed the risk factor questionnaire that included questions about their personal cancer history. For this analysis we excluded 89 relatives with a proxy respondent; 115 enrolled mothers of probands diagnosed with breast cancer from 1995–1998 because in those early years of recruitment, we did not collect the risk factor questionnaire for unaffected mothers; and 44 adult daughters with a personal history of breast cancer because throughout the study we did not enroll any unaffected adult daughters. Thus, this analysis included personal cancer history reports by 3,136 female first-degree relatives (mothers and sisters). These relatives were related to 1,716 female probands.

## Data collection

For probands, trained interviewers administered a family history questionnaire by telephone and a risk factor questionnaire by home visit in English, Spanish, Cantonese or Mandarin. The family history questionnaire enumerated all biological first-degree relatives, recorded their date of birth, vital status, date of death if deceased, cancer history (i.e., cancer site, age at diagnosis), and ascertained second and higher degree relatives with a cancer diagnosis. The risk factor questionnaire included questions about race/ethnicity, education, country of birth, and first language learned. If English was not the participant's first language, English language proficiency was assessed in the questionnaire by asking "Which of these choices best describes how well you speak English": "well," "medium," "little," or "not at all." The questionnaire also asked about personal cancer history (i.e., cancer site, age at diagnosis).

Participating relatives completed the same risk factor questionnaire as the probands, either by home visit (San Francisco Bay Area residents) or by telephone in English, Spanish, Cantonese or Mandarin. Race/ethnicity was self-reported, based on the screening interview for probands and the risk factor questionnaire for relatives.

## Comparisons of cancer history data

To assess the accuracy of female probands' cancer family history reports and of female relatives' personal cancer history reports, we performed three sets of comparisons. First, we compared proband family history reports (i.e., breast and other cancers in first-degree female relatives) to personal cancer history reports by relatives; second, we compared the proband family history reports to California Cancer Registry records; and third, we compared personal history reports of breast cancer by relatives to California Cancer Registry records. Figure 1 shows the number of probands and relatives included in each comparison.

**Proband reports vs. relative reports.—**Assuming that a self-reported cancer is more accurate than a report by another family member, we used the first-degree relatives' reports as the reference standard to assess the accuracy of the probands' cancer family history reports. We compared the family history reports of 1,716 probands to the personal cancer history reports of 3,136 enrolled female first-degree relatives. This analysis included only a subset of all enrolled probands since not all enumerated relatives were alive, resided in North America, had proband permission to be contacted, or enrolled in NC-BCFR (22). For this comparison, we grouped melanoma and other types of skin cancer under the category skin cancer, as reports of melanoma are often not distinguished from other skin cancers.

**Proband reports vs. cancer registry records.—**Since the probands were diagnosed with breast cancer in California and many relatives also lived in California, we used the state-wide California Cancer Registry records as the reference standard to assess the accuracy of the probands' cancer family history reports. All female first-degree relatives enumerated by the probands in the family history questionnaire (N=13,906), regardless of vital status, were linked to California Cancer Registry records in 2013 to identify incident cancers diagnosed since 1973 in the Greater San Francisco Bay Area (when this registry became part of the Surveillance, Epidemiology and End Results (SEER) Program) or diagnosed since 1988 elsewhere in California (when all cancers in California were mandated to be reported). Through probabilistic record linkage, 850 female first-degree relatives were identified with one or more cancer diagnoses prior to the completion of the family history questionnaire by the probands. These included 514 relatives with a breast cancer diagnosis only, 299 with a cancer diagnosis at other sites only, and 37 with cancer diagnosed in the breast and other sites. These 850 female relatives were related to 756 probands. We compared the cancer registry report for these 850 relatives with cancer to the family history reports by 756 probands to determine whether the cancer diagnoses in the cancer registry were also reported by the probands. Thus, this analysis included only a subset of all enrolled probands since not all relatives were diagnosed in California. The cancer records distinguished between *in situ* and invasive breast cancers; therefore, we examined proband reporting for breast cancer overall, as well as separately for *in situ* and invasive breast cancer. For this comparison we excluded skin cancers and melanoma, because non-

melanoma skin cancers are not ascertained in the cancer registry and proband reports may not have distinguished between melanoma and other skin cancers.

**Relative report vs. cancer registry records.—**Since we used the relatives' self-report of cancer as the reference standard in the first comparison (proband vs. relative reports), we used the California Cancer Registry records to assess the accuracy of the relatives' self-report of breast cancer. For the 551 female relatives identified with a breast cancer diagnosis by linkage with the California Cancer Registry, we identified 182 who were enrolled in NC-BCFR and reported their personal cancer history. We determined whether the breast cancer diagnoses identified in the cancer registry were also reported by the relatives and probands. We examined relative reporting for breast cancer overall, as well as for *in situ* and invasive breast cancer.

## Statistical analysis

We performed three sets of comparisons. First, we assessed the accuracy of proband-reported cancer family history compared with the relative personal cancer history report as the reference standard by calculating sensitivity and specificity. *Sensitivity* was defined as the proportion of relatives with cancer (based on relative self-report) correctly classified by probands. *Specificity* was defined as the proportion of relatives without cancer correctly classified by probands. We also assessed overall agreement between proband report and relative report using the kappa statistic (24). For these analyses, every eligible relative was included for each cancer site, as either a positive or negative report (by both the proband and the relative). A relative with a primary cancer at multiple sites was counted as having a positive report for each site.

Second, we assessed the accuracy of proband-reported cancer family history compared with cancer registry records as the reference standard by calculating sensitivity defined as the proportion of relatives with cancer (based on cancer registry records) correctly classified by probands. For this comparison, we could not calculate specificity, because we included only relatives with a cancer identified by the cancer registry.

Third, we assessed the accuracy of the relative report of a personal history of breast cancer compared with cancer registry records as the reference standard by calculating sensitivity defined as the proportion of relatives with breast cancer (based on cancer registry records) correctly classified by the relative report.

We calculated sensitivity and specificity using generalized estimating equation (GEE) with exchangeable correlation structure to account for the variation in the number of relatives per proband and correlation of reports within families (25,26). We estimated 95% confidence intervals (CI) using backward transformation. For breast cancer, we also performed GEE analyses to assess whether sensitivity and specificity of proband-reported family history varied by proband characteristics, such as race/ethnicity (non-Hispanic white, Hispanic white, African American (non-Hispanic or Hispanic), Chinese, Filipina, Japanese, Other Asian American/Pacific Islander including Hispanic Asian, Other (mixed race, Native American, or unspecified race/ethnicity)), age at questionnaire completion (<50 vs. ≥50 years), education (high school graduate or less vs. some college or more), birth place (U.S.-

born vs. foreign-born), and self-assessed English language proficiency (high proficiency (well or English only) vs. low proficiency (medium, little, not at all)). Two-sided *P*-values from Wald tests using empirical standard errors are reported, with *P*-values <0.05 considered statistically significant. Analyses were conducted using SAS version 9.4 software (SAS Institute, Inc., Cary, NC).

## Results

### Accuracy of female probands' reports vs. female relative's reports

Comparing cancer family history reports by 1,716 probands to personal cancer history reports by 3,136 enrolled female first-degree relatives, we found that 300 relatives reported a personal history of breast cancer, compared with 279 relatives with breast cancer reported by probands (Table 1). Sensitivity of proband-reported family history of breast cancer was 93%, with 21 breast cancers under-reported by probands. Probands over-reported breast cancer in six relatives that were not confirmed by relative reports. Specificity for breast cancer was over 99%. Overall, agreement for breast cancer between proband and relative reports was high (kappa = 0.97 for mothers and 0.94 for sisters).

There were 195 relative reports of cancer at sites other than the breast (Table 1). Probands under-reported these cancers, with only 119 of the 195 cancers reported by probands in the family history questionnaire. Conversely, probands over-reported 23 cancers that were not reported by their relatives. For the most frequently reported cancers (ovarian, skin, cervical, colorectal, uterine, and lung cancer), sensitivity ranged widely from 42.5% for cervical cancer to 81% for ovarian cancer. Specificity ranged from 99.7 to 99.8. The kappa statistic for overall agreement ranged from 0.55 (uterine and skin cancers) to 0.84 (lung cancer). As shown in the footnotes of Table 1, in some instances probands reported a different cancer than relatives (e.g., ovarian instead of cervical cancer), whereas in other instances probands reported a cancer not reported by relatives.

For breast cancer, differences in sensitivity by proband characteristics were small and not statistically significant (Table 2). Sensitivity was marginally lower for Hispanic whites (87.3%) than non-Hispanic whites (95.1%, *P*=0.07) probands, but similarly high for African Americans (93.7%) and Asian Americans (95.4%). Sensitivity did not differ by age, education, and place of birth, but was marginally lower for probands with low vs. high English language proficiency (83.3% vs. 93.5%, *P*=0.12). Specificity differed little by race/ethnicity, with all values ≥99.7%, and did not vary by other proband characteristics.

### Accuracy of female probands' reports vs. cancer registry records

Linkage of all proband-enumerated first-degree relatives (mothers, sisters, adult daughters, N=13,906) with California Cancer Registry records identified 850 relatives with cancer (551 with breast cancer). These 850 relatives were related to 756 probands. Of the 551 breast cancers identified in cancer registry records, 526 breast cancers were also reported by the probands in the family history questionnaire, with a sensitivity of 95.5% for breast cancer overall, 96.2% for invasive breast cancer, and 88.5% for *in situ* breast cancer (Table 3). Sensitivity of proband reports was slightly higher for breast cancer in mothers (97.6%) and

daughters (100%) than in sisters (92.7%). For other cancer sites, sensitivity was considerably lower, ranging from 22.7% for cervical cancer to 79.5% for ovarian cancer.

As shown in Table 4, for breast cancer, sensitivity of proband report did not differ by the proband's age or education, was marginally lower for Hispanic whites vs. non-Hispanic whites (91.2% vs. 96.4%, $P$=0.05) and for foreign-born vs. U.S.-born probands (92.0% vs. 96.2%, $P$=0.10), and was significantly lower for probands with limited vs. high English language proficiency (80.0% vs. 96.1%, $P$<0.01).

### Accuracy of female relatives' reports vs. cancer registry records

Of 551 relatives with a breast cancer diagnosis according to cancer registry records, 182 had enrolled in NC-BCFR. Of these, 173 relatives reported a breast cancer diagnosis, with a sensitivity of 95.9% (95% CI, 91.9–98.0) (Table 5). Sensitivity was higher for invasive (98.7%) than *in situ* (73.1%) breast cancer and ranged from 94.5% among African Americans (1 under-report) to 100% among non-Hispanic whites for invasive disease. For proband reports, sensitivity for invasive breast cancer was also high (90.3%, 95% CI=84.6–94.1) and ranged from 84.7% among Hispanic whites to 96.1% among Asian Americans.

## Discussion

In this racially and ethnically diverse population-based family study, female probands reported first-degree family history of female breast cancer with high accuracy, with a sensitivity of 93% when compared with their female relatives' reports of personal cancer history and 95.5% when compared with California Cancer Registry records. A similarly high sensitivity of 95.9% was found for female relatives' report of a personal history of breast cancer when compared with cancer registry records. Sensitivity varied little by race/ethnicity and other proband characteristics, except for lower sensitivity for Hispanic white probands and those with low English language proficiency.

These findings agree with other studies that reported sensitivities ranging from 95–99% for first-degree family history of breast cancer reported by breast cancer patients (9,10,27). High reporting accuracy was also found for family history of breast cancer reported by prostate cancer and glioma patients (28,29), with somewhat lower sensitivity (73–83%) for reports by lymphoma and colorectal cancer patients (13,30,31). In contrast, a recent general population survey found lower sensitivity of 64.9% for reporting breast cancer in first-degree relatives (32). These findings suggest that women with breast or other cancers may be more knowledgeable about breast cancer in relatives than women in the general population. In families with multiple relatives with breast cancer, there may be more communication about their cancers, and therefore more accurate family history reporting. It is also possible that family members who live in close geographic proximity may be more communicative about their cancers. In the present study, sensitivity was similarly high for proband reports vs. relative reports (93%) where relatives lived anywhere in the U.S, and for proband reports vs. cancer registry records (95.5%) where relatives lived in California. It has been shown that communication about family cancer history is less frequent than desired (33–35) and may be influenced by cultural beliefs, values, and taboos that may hinder family communication (36–39).

Studies have shown that the source of the study population can affect the level of accuracy of reported cancer family history, with more accurate reporting in clinic-based studies than population-based studies (10,11). In the present study, where probands were selected from population-based cancer registries, the accuracy of reporting a family history of breast cancer was high and comparable to other studies.

The present finding that relatives reported a personal history of breast cancer with high accuracy (sensitivity 95.9% when compared with cancer registry reports) is consistent with other studies (5–7). This sensitivity estimate is similar to the estimate of 96.4% reported by the California Teachers Study (6). We found seven of nine relatives who did not self-report a prior breast cancer had a diagnosis of *in situ* breast cancer per cancer registry records. Similarly, other studies reported higher accuracy for a personal history of invasive than *in situ* breast cancer (6,7). It is possible that some individuals with *in situ* breast cancer did not consider it to be cancer and therefore did not report it. This may also explain the lower sensitivity for proband-reported *in situ* breast cancer compared with invasive breast cancer in first-degree relatives. Nevertheless, the present findings support the use of relatives' reports as a reference to calculate sensitivity and other measures of accuracy of the proband report of breast cancer family history.

The present study is the first to examine the accuracy of proband-reported breast cancer family history for the major U.S. racial/ethnic groups. Sensitivity was similarly high across race/ethnicity when comparing proband report with relative report (ranging from 93.7% −95.4% for African Americans, non-Hispanic whites, and Asian Americans) or with cancer registry records (ranging from 95.6%−97.4% for Asian Americans, non-Hispanic whites, and African Americans), but sensitivity was marginally lower for Hispanic whites (87.3% and 91.2%, respectively), and Hispanic white probands with low English proficiency (84.6% and 78.8%, respectively). Similarly, Tehranifar et al. found lower sensitivity for cancer family history reports by Spanish-speaking participants (15). It is possible that a relative's lack of understanding the diagnosis may have contributed to the under-reporting by the proband. Larger sample sizes, however, are needed to evaluate the relation between accuracy of cancer family history and English proficiency. Another study found no statistically significant difference in the accuracy of proband-reported breast cancer family history by proband race/ethnicity, although that study included only 44 non-white probands (10). We found that sensitivity did not vary by other proband characteristics (i.e., age, education, or place of birth). In some studies (9,10,40), accuracy did not vary with respondents' age or education, whereas other studies found more accurate reporting by younger (10,13) or more educated (13) individuals.

Consistent with other studies (10,11,13,14), we found the accuracy of proband-reported family history was lower for less common cancers. Sensitivity estimates were similar to those summarized by Fiederling et al. (14) for skin and cervical cancer (31% and 50%, respectively) and lung cancer (ranging from 71–84%). Furthermore, we found that sensitivity was lower when using cancer registry records vs. relatives' reports as the reference (ovarian cancer 79.5% vs. 81.0%; colorectal cancer 65.3% vs. 78.6%; cervical cancer 22.7% vs. 42.5%). The comparison of relative-reported cancers with cancer registry records also revealed lower sensitivity for ovarian, colorectal, and cervical cancer compared

with breast cancer. These findings reinforce the importance of validating both family history and personal history reports of cancers other than breast cancer.

The present study has several important strengths. The population-based design of this family study identified probands through regional cancer registries allowing us to link first-degree relatives to cancer registry records and identify cancers not reported by probands. Although the cancer registry comparison was limited to relatives diagnosed in a limited geographic area and during a limited time frame, it included cancer reports for both live and deceased relatives, but was limited to sensitivity estimates. The family design allowed us to directly compare cancer family history reports by probands with personal cancer history reports by over 3,000 relatives and to calculate additional measures of accuracy (i.e., specificity and kappa statistic). This method of validation relies on the accuracy of personal cancer history reports, which we and others (5–7) found to be high for breast cancer. The comparison of proband with relatives' reports allows validation of cancer reports in relatives residing in a wide geographic area that may not be covered by regional cancer registries, but such validation is limited to living relatives. Lastly, given the oversampling of racial/ethnic minority breast cancer families, we were able to evaluate the accuracy of cancer family history reports for the major U.S. racial/ethnic groups, including Asian subgroups, and to explore the influence of proband characteristics such as birth place and English language proficiency on accuracy of proband reports.

The racial/ethnic diversity of the breast cancer families enrolled in NC-BCFR also highlights some limitations of the present analysis. We were not able to enroll relatives who lived outside of North America to obtain self-reported histories of breast and other cancers, or to verify proband cancer history reports in those relatives through medical records. Furthermore, not all probands gave us permission to contact their first-degree relatives, particularly African American and Chinese probands (22). Thus, for a relatively large proportion of probands (46%), we could not confirm their cancer family history reports with relative reports. It is reassuring, however, that for breast cancer the sensitivity was similarly high when compared with either relative reports or cancer registry records. Our study was also limited to validation of cancers in first-degree relatives. Other studies have shown that accuracy of reported breast cancer is lower for second- and third-degree relatives (9–11), thus, our findings are not generalizable to more distant relatives. For cancers other than breast cancer, our sample size was too small to assess racial/ethnic differences in accuracy of family history reports. We collected cancer family history data from probands by telephone interview. It is possible that the accuracy of proband reports is different in studies that collect family history data by mail questionnaire or in-person interview. Since we evaluated the accuracy of cancer family history reports in women with breast cancer who enrolled in a long-term follow-up study, our findings may not be generalizable to those who declined enrollment or the overall population. Lastly, because nearly half of probands had other family members enrolled in NC-BCFR, discussion of cancer history among relatives may have resulted in higher accuracy of proband-reported family history. Thus, our findings may not be generalizable to other study settings where only one family member reports on cancer family history.

In conclusion, we found that sensitivity of proband-reported breast cancer family history was similarly high for non-Hispanic whites, African Americans, and Asian Americans, but somewhat lower for Hispanic whites and for those with limited English language proficiency. Sensitivity was lower for other cancers, underlining the importance of assessing accurate cancer family histories, from multiple family members if possible, and validating family history reports of cancers other than breast cancer with cancer registry records or other sources such as medical records and pathology reports. For women with breast cancer, accuracy of breast cancer family history reports was high and such reports can be used when other validation methods are not available.

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## Abbreviations:

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| **BCFR** | Breast Cancer Family Registry |
| **CI** | confidence interval |
| **NC-BCFR** | Northern California Breast Cancer Family Registry |
| **GEE** | generalized estimating equation |
| **SEER** | Surveillance, Epidemiology and End Results |
| **U.S.** | United States |

## References

1. Pharoah PD, Day NE, Duffy S, Easton DF, Ponder BA. Family history and the risk of breast cancer: a systematic review and meta-analysis. Int J Cancer 1997;71(5):800–9. [PubMed: 9180149]
2. Collaborative Group on Hormonal Factors in Breast Cancer. Familial breast cancer: collaborative reanalysis of individual data from 52 epidemiological studies including 58,209 women with breast cancer and 101,986 women without the disease. Lancet 2001;358(9291):1389–99. [PubMed: 11705483]
3. Ramsey SD, Yoon P, Moonesinghe R, Khoury MJ. Population-based study of the prevalence of family history of cancer: implications for cancer screening and prevention. Genet Med 2006;8(9): 571–5. [PubMed: 16980813]
4. Mai PL, Wideroff L, Greene MH, Graubard BI. Prevalence of family history of breast, colorectal, prostate, and lung cancer in a population-based study. Public Health Genomics 2010;13(7–8):495–503. [PubMed: 20389042]

5. Bergmann MM, Calle EE, Mervis CA, Miracle-McMahill HL, Thun MJ, Health CW. Validity of self-reported Cancers in a Propsective Cohort Study in Comparison with Data from State Cancer Registries. Am J Epidemiol 1998;147(6):556–62. [PubMed: 9521182]
6. Parikh-Patel A, Allen M, Wright WE. Validation of self-reported cancers in the California Teachers Study. Am J Epidemiol 2003;157(6):539–45. [PubMed: 12631544]
7. D'Aloisio AA, Nichols HB, Hodgson ME, Deming-Halverson SL, Sandler DP. Validity of self-reported breast cancer characteristics in a nationwide cohort of women with a family history of breast cancer. BMC Cancer 2017;17(1):692. [PubMed: 29058598]
8. Cho S, Shin A, Song D, Park JK, Kim Y, Choi JY, et al. Validity of self-reported cancer history in the health examinees (HEXA) study: A comparison of self-report and cancer registry records. Cancer Epidemiol 2017;50(Pt A):16–21. [PubMed: 28763723]
9. Theis B, Boyd N, Lockwood G, Tritchler D. Accuracy of family cancer history in breast cancer patients. Eur J Cancer Prev 1994;3(4):321–7. [PubMed: 7950886]
10. Ziogas A, Anton-Culver H. Validation of family history data in cancer family registries. Am J Prev Med 2003;24(2):190–8. [PubMed: 12568826]
11. Murff HJ, Spigel DR, Syngal S. Does this patient have a family history of cancer? An evidence-based analysis of the accuracy of family cancer history. JAMA 2004;292(12):1480–9. [PubMed: 15383520]
12. Augustinsson A, Ellberg C, Kristoffersson U, Borg A, Olsson H. Accuracy of self-reported family history of cancer, mutation status and tumor characteristics in patients with early onset breast cancer. Acta Oncol 2018;57(5):595–603. [PubMed: 29164969]
13. Kerber RA, Slattery ML. Comparison of self-reported and database-linked family history of cancer data in a case-control study. Am J Epidemiol 1997;146(3):244–8. [PubMed: 9247008]
14. Fiederling J, Shams AZ, Haug U. Validity of self-reported family history of cancer: A systematic literature review on selected cancers. Int J Cancer 2016;139(7):1449–60. [PubMed: 27222437]
15. Tehranifar P, Wu HC, Shriver T, Cloud AJ, Terry MB. Validation of family cancer history data in high-risk families: the influence of cancer site, ethnicity, kinship degree, and multiple family reporters. Am J Epidemiol 2015;181(3):204–12. [PubMed: 25568166]
16. Li R, Gilliland FD, Baumgartner KB, Samet J. Family history and risk of breast cancer in hispanic and non-hispanic women: the New Mexico Women's Health Study. Cancer Causes Control 2001;12(8):747–53. [PubMed: 11562115]
17. Pinsky PF, Kramer BS, Reding D, Buys S, Team PP. Reported family history of cancer in the prostate, lung, colorectal, and ovarian cancer screening trial. Am J Epidemiol 2003;157(9):792–9. [PubMed: 12727673]
18. Chlebowski RT, Chen Z, Anderson GL, Rohan T, Aragaki A, Lane D, et al. Ethnicity and breast cancer: factors influencing differences in incidence and outcome. J Natl Cancer Inst 2005;97(6): 439–48. [PubMed: 15770008]
19. Hall IJ, Moorman PG, Millikan RC, Newman B. Comparative analysis of breast cancer risk factors among African-American women and White women. Am J Epidemiol 2005;161(1):40–51. [PubMed: 15615914]
20. Simon MS, Korczak JF, Yee CL, Daling JR, Malone KE, Bernstein L, et al. Racial differences in the familial aggregation of breast cancer and other female cancers. Breast Cancer Res Treat 2005;89(3):227–35. [PubMed: 15754120]
21. Scheuner MT, McNeel TS, Freedman AN. Population prevalence of familial cancer and common hereditary cancer syndromes. The 2005 California Health Interview Survey. Genet Med 2010;12(11):726–35. [PubMed: 20921897]
22. John EM, Sangaramoorthy M, Koo J, Whittemore AS, West DW. Enrollment and biospecimen collection in a multiethnic family cohort: the Northern California site of the Breast Cancer Family Registry. Cancer Causes Control 2019;30(4):395–408. [PubMed: 30835011]
23. John EM, Hopper JL, Beck JC, Knight JA, Neuhausen SL, Senie RT, et al. The Breast Cancer Family Registry: an infrastructure for cooperative multinational, interdisciplinary and translational studies of the genetic epidemiology of breast cancer. Breast Cancer Res 2004;6(4):R375–89. [PubMed: 15217505]

24. Landis JR, Koch GG. The measurement of observer agreement for categorical data. Biometrics 1977;33(1):159–74. [PubMed: 843571]
25. Smith PJ, Hadgu A. Sensitivity and specificity for correlated observations. Stat Med 1992;11(11): 1503–9. [PubMed: 1410962]
26. Sternberg MR, Hadgu A. A GEE approach to estimating sensitivity and specificity and coverage properties of the confidence intervals. Stat Med 2001;20(9–10):1529–39. [PubMed: 11343372]
27. Verkooijen HM, Fioretta G, Chappuis PO, Vlastos G, Sappino AP, Benhamou S, et al. Set-up of a population-based familial breast cancer registry in Geneva, Switzerland: validation of first results. Ann Oncol 2004;15(2):350–3. [PubMed: 14760133]
28. King TM, Tong L, Pack RJ, Spencer C, Amos CI. Accuracy of family history of cancer as reported by men with prostate cancer. Urology 2002;59(4):546–50. [PubMed: 11927311]
29. Airewele G, Adatto P, Cunningham J, Mastromarino C, Spencer C, Sharp M, et al. Family history of cancer in patients with glioma: a validation study of accuracy. J Natl Cancer Inst 1998;90(7): 543–4. [PubMed: 9539252]
30. Chang ET, Smedby KE, Hjalgrim H, Glimelius B, Adami HO. Reliability of self-reported family history of cancer in a large case-control study of lymphoma. J Natl Cancer Inst 2006;98(1):61–8. [PubMed: 16391372]
31. Mitchell RJ, Brewster D, Campbell H, Porteous ME, Wyllie AH, Bird CC, et al. Accuracy of reporting of family history of colorectal cancer. Gut 2004;53(2):291–5. [PubMed: 14724166]
32. Mai PL, Garceau AO, Graubard BI, Dunn M, McNeel TS, Gonsalves L, et al. Confirmation of family cancer history reported in a population-based survey. J Natl Cancer Inst 2011;103(10):788–97. [PubMed: 21562245]
33. Bowen DJ, Hay JL, Harris-Wai JN, Meischke H, Burke W. All in the family? Communication of cancer survivors with their families. Fam Cancer 2017;16(4):597–603. [PubMed: 28374161]
34. Pho K, Geller A, Schroy PC 3rd. Lack of communication about familial colorectal cancer risk associated with colorectal adenomas (United States). Cancer Causes Control 2000;11(6):543–6. [PubMed: 10880036]
35. Kaphingst KA, Goodman M, Pandya C, Garg P, Stafford J, Lachance C. Factors affecting frequency of communication about family health history with family members and doctors in a medically underserved population. Patient Educ Couns 2012;88(2):291–7. [PubMed: 22197261]
36. Sheppard VB, Christopher J, Nwabukwu I. Breaking the silence barrier: opportunities to address breast cancer in African-born women. J Natl Med Assoc 2010;102(6):461–8. [PubMed: 20575210]
37. Kinney AY, Gammon A, Coxworth J, Simonsen SE, Arce-Laretta M. Exploring attitudes, beliefs, and communication preferences of Latino community members regarding BRCA1/2 mutation testing and preventive strategies. Genet Med 2010;12(2):105–15. [PubMed: 20061960]
38. Yoon SY, Thong MK, Taib NA, Yip CH, Teo SH. Genetic counseling for patients and families with hereditary breast and ovarian cancer in a developing Asian country: an observational descriptive study. Fam Cancer 2011;10(2):199–205. [PubMed: 21318382]
39. Gibson EG, Gage JC, Castle PE, Scarinci IC. Perceived susceptibility to cervical cancer among African American women in the Mississippi Delta: Does adherence to screening matter? Womens Health Issues 2019;29(1):38–47. [PubMed: 30401612]
40. Parent ME, Ghadirian P, Lacroix A, Perret C. Accuracy of reports of familial breast cancer in a case-control series. Epidemiology 1995;6(2):184–6. [PubMed: 7742408]

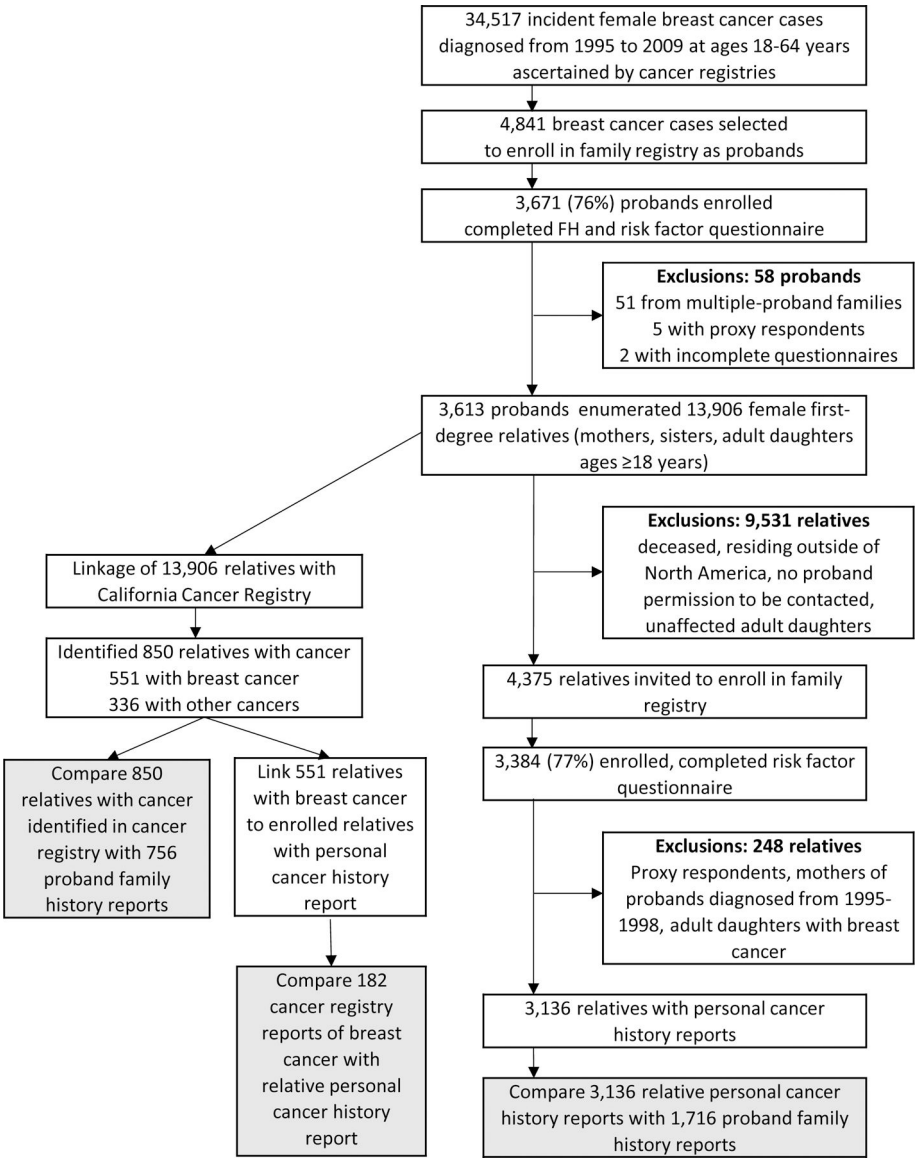


**Figure 1.**
Flow chart of study population

**Table 1.**

Female probands' reports (N=1,716) of female first-degree family history of breast and other cancers [a] compared with female relatives' reports (N=3,136) of personal cancer history [b], Northern California Breast Cancer Family Registry

| | Positive relative [c] report | | Negative relative [c] report | | Sensitivity % (95% CI) [d] | Specificity % (95% CI) [d] | Overall agreement [e] |
|---|---|---|---|---|---|---|---|
| | Positive proband report | Negative proband report | Positive proband report | Negative proband report | | | |
| **Breast cancer** [f] | 279 | 21 | 6 | 2,830 | 93.0 (89.5–95.4) | 99.8 (99.5–99.9) | 0.95 |
| Type of relative | | | | | | | |
| Mother | 61 | 3 | 0 | 322 | 95.3 (86.5–98.5) | 100 | 0.97 |
| Sister | 218 | 18 | 6 | 2,508 | 92.4 (88.2–95.1) | 99.8 (99.5–99.9) | 0.94 |
| **Other cancers** [g] | 119 | 76 | 23 | 2,918 | | | |
| Ovarian [h] | 17 | 4 [i] | 6 [l] | 3,109 | 81.0 (58.8–92.7) | 99.8 (99.6–99.9) | 0.77 |
| Skin [h] | 21 | 24 [i] | 9 [m] | 3,082 | 46.4 (32.5–60.8) | 99.7 (99.4–99.8) | 0.55 |
| Cervical [h] | 18 | 23 [j] | 2 [m] | 3,093 | 42.5 (28.3–58.0) | 99.9 (99.7–100) | 0.59 |
| Colorectal | 11 | 3 [i] | 2 [m] | 3,120 | 78.6 (50.6–92.9) | 99.9 (99.7–100) | 0.81 |
| Uterine [h] | 15 | 18 [k] | 6 [n] | 3,097 | 45.5 (29.6–62.3) | 99.8 (99.6–99.9) | 0.55 |
| Lung [h] | 8 | 3 [i] | 0 | 3,125 | 72.7 (41.4–91.0) | 100 | 0.84 |

Abbreviation: CI, confidence interval.

[a] Probands could report multiple cancers for each relative in the family history questionnaire.

[b] Relatives could report multiple cancers in the personal cancer history section of the risk factor questionnaire.

[c] Full and half-sisters and mothers.

[d] Calculated using GEE to account for multiple members in one family.

[e] Kappa statistic (0.2 =slight, 0.21–0.4=fair, 0.41–0.6=moderate, 0.61–0.8=substantial, 0.81–1.0=almost perfect).

[f] Relatives with breast cancer only or with multiple primary cancers including breast cancer.

[g] Relatives with at least one primary non-breast cancer.

[h] Relatives with cancer(s) at the site specified only or those with multiple primary cancers including one at the site specified.

[i] Relatives reported 4 ovarian, 24 skin, 3 colorectal and 3 lung cancers; probands reported no cancer.

[j] Relatives reported 23 cervical cancers; probands reported 1 breast, 1 ovarian, and 4 uterine cancers, and 17 reported no cancer.

[k] Relatives reported 18 uterine cancers; probands reported 2 ovarian cancers, and 16 reported no cancer.

[l] Probands reported 6 ovarian cancers; relatives reported 2 uterine and 1 cervical cancer, and 3 relatives reported no cancer.

[m] Probands reported 9 skin cancers, 2 cervical, and 2 colorectal cancers; relatives reported no cancer.

[n] Probands reported 6 uterine cancers; relatives reported 4 cervical cancers, and 2 relatives reported no cancer.

**Table 2.**

Predictors of sensitivity and specificity of female first-degree family history of breast cancer reported by female probands [a] compared with female relatives' reports of personal cancer history [b], Northern California Breast Cancer Family Registry

| | Positive relative report [c] | | Negative relative report [c] | | | | |
|---|---|---|---|---|---|---|---|
| | Positive proband report | Negative proband report | Positive proband report | Negative proband report | Sensitivity % (95% CI) [d] | *P*-value [e] | Specificity % (95% CI) [d] |
| **Breast cancer** [f] | 279 | 21 | 6 | 2,830 | 93.0 (89.5–95.4) | | 99.8 (99.5–99.9) |
| Proband's race/ethnicity [g] | | | | | | | |
| Non-Hispanic white | 98 | 5 | 2 | 610 | 95.1 (88.9–98.0) | | 99.7 (98.7–99.9) |
| Hispanic white | 70 | 10 | 3 | 1,001 | 87.3 (78.0–93.1) | 0.07 | 99.7 (99.1–99.9) |
| African American | 62 | 4 | 1 | 736 | 93.7 (84.4–97.6) | 0.70 [h] | 99.9 (99.0–100) |
| Asian American | 48 | 2 | 0 | 455 | 95.4 (83.7–98.8) | 0.87 | 100 |
| Chinese | 14 | 1 | 0 | 161 | 93.3 (64.8–99.1) | 0.76 | 100 |
| Filipina | 12 | 0 | 0 | 192 | 100 | n/a | 100 |
| Japanese | 14 | 0 | 0 | 54 | 100 | n/a | 100 |
| Other Asian/Pacific Islander | 8 | 1 | 0 | 48 | 76.1 (33.9–95.2) | 0.30 | 100 |
| Other | 1 | 0 | 0 | 28 | 100 | n/a | 100 |
| Proband's age (years) [i] | | | | | | | |
| <50 | 89 | 6 | 2 | 1,323 | 93.7 (86.6–97.1) | 0.73 | 99.8 (99.4–100) |
| ≥50 | 190 | 15 | 4 | 1,507 | 92.6 (88.2–95.5) | | 99.7 (99.3–99.9) |
| Proband's education [j] | | | | | | | |
| High school graduate or less | 64 | 6 | 3 | 926 | 91.3 (81.9–96.1) | 0.60 | 99.7 (99.0–99.9) |
| Some college or more | 215 | 15 | 3 | 1,898 | 93.3 (89.2–95.9) | | 99.8 (99.5–99.9) |
| non-Hispanic white | | | | | | | |
| High school graduate or less | 20 | 0 | 1 | 116 | 100 | n/a | 99.1 [k] |
| Some college or more | 78 | 5 | 1 | 492 | 94.0 (86.3–97.5) | | 99.8 (98.6–100) |
| Hispanic white | | | | | | | |
| High school graduate or less | 30 | 4 | 1 | 540 | 87.9 (71.7–95.4) | 0.93 | 99.8 (98.7–100) |
| Some college or more | 40 | 6 | 2 | 458 | 87.0 (73.9–94.0) | | 99.6 (98.3–99.9) |

| | Positive relative report [c] | | Negative relative report [c] | | | | |
|---|---|---|---|---|---|---|---|
| | Positive proband report | Negative proband report | Positive proband report | Negative proband report | Sensitivity % (95% CI) [d] | *P*-value [e] | Specificity % (95% CI) [d] |
| African American | | | | | | | |
| High school graduate or less | 10 | 1 | 1 | 214 | 90.8 (55.3–98.7) | 0.82 | 99.5 (96.7–99.9) |
| Some college or more | 52 | 3 | 0 | 521 | 93.4 (81.3–97.9) | | 100 |
| Chinese | | | | | | | |
| High school graduate or less | 0 | 1 | 0 | 34 | n/a | | 100 |
| Some college or more | 14 | 0 | 0 | 127 | 100 | | 100 |
| Proband's place of birth [j] | | | | | | | |
| U.S.-born | 224 | 15 | 6 | 2,018 | 93.7 (89.9–96.2) | 0.32 | 99.7 (99.3–99.9) |
| Foreign-born | 55 | 6 | 0 | 812 | 90.1 (79.8–95.4) | | 100 |
| Hispanic white | | | | | | | |
| U.S.-born | 45 | 6 | 3 | 534 | 88.0 (75.8–94.5) | 0.80 | 99.4 (98.3–99.8) |
| Foreign-born | 25 | 4 | 0 | 467 | 86.1 (68.2–94.7) | | 100 |
| Chinese | | | | | | | |
| U.S.-born | 6 | 0 | 0 | 63 | 100 | n/a | 100 |
| Foreign-born | 8 | 1 | 0 | 98 | 88.9 (50.0–98.5) | | 100 |
| Proband's English language proficiency [j] | | | | | | | |
| Spoken well | 262 | 18 | 6 | 2,405 | 93.5 (90.0–95.9) | 0.12 | 99.8 (99.4–99.9) |
| Not spoken well | 15 | 3 | 0 | 399 | 83.3 (59.1–94.5) | | 100 |
| Hispanic whites | | | | | | | |
| Spoken well | 59 | 8 | 3 | 678 | 87.9 (77.5–93.8) | 0.76 | 99.6 (98.6–99.9) |
| Not spoken well | 11 | 2 | 9 | 318 | 84.6 (54.9–96.1) | | 100 |
| Chinese | | | | | | | |
| Spoken well | 13 | 0 | 0 | 108 | 100 | n/a | 100 |
| Not spoken well | 1 | 1 | 0 | 45 | 50.0 (5.9–94.1) | | 100 |

Abbreviation: CI, confidence interval.

[a] Probands could report multiple cancers for each relative in the family history questionnaire.

[b] Relatives could report multiple cancers in the personal cancer history section of the risk factor questionnaire.

[c] Full and half-sisters and mothers.

[d] Calculated using GEE to account for multiple members in one family.

[e] Two-sided *P*-value from Wald test using empirical standard error.

[f] Relatives with breast cancer only or with multiple primary cancers including breast cancer.

[g] Race/ethnicity is self-reported based on the probands' screening interview. Given small counts for some racial/ethnic groups, we combined groups as follows: African Americans include Black Hispanics; Other Asian/Pacific Islanders includes Asian Hispanics; Other includes mixed race, Native Americans, and unspecified race/ethnicity.

[h] *P*-value for each racial/ethnic group compared with non-Hispanic whites.

[i] Age at questionnaire completion.

[j] Numbers do not add up due to missing data on proband's education level, place of birth, and English language proficiency.

[k] Model did not converge to estimated 95% CI.



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## Table 3.

Female probands' report of family history of breast and other cancers [a] in female first-degree relatives compared with cancer registry records, Northern California Breast Cancer Family Registry

| | Female first-degree relatives [b] with cancer in the California Cancer Registry | | |
|---|---|---|---|
| | N | Also reported by probands | Sensitivity % (95% CI) [c] of proband report |
| **All breast cancers** [d] | 551 | 526 | 95.5 (93.4–96.9) |
| Type of cancer | | | |
| *In situ* | 52 | 46 | 88.5 (76.6–94.7) |
| Invasive | 499 | 480 | 96.2 (94.1–97.6) |
| Type of relative | | | |
| Mother | 293 | 286 | 97.6 (95.1–98.9) |
| Sister | 249 | 231 | 92.7 (88.8–95.3) |
| Daughter | 9 | 9 | 100 |
| **Other cancers** [e] | 336 | 240 | |
| Ovarian [f] | 44 | 35 | 79.5 (65.1–89.0) |
| Cervical [f] | 62 | 14 | 22.7 (13.9–34.9) |
| Colorectal [f] | 50 | 33 | 65.3 (51.2–77.1) |
| Uterine [f] | 34 | 18 | 52.9 (36.5–68.8) |
| Lung [f] | 37 | 27 | 76.2 (56.0–84.6) |

Abbreviation: CI, confidence interval.

[a] Probands could report multiple cancers for each relative in the family history questionnaire.

[b] Full and half-sisters, mothers, and affected adult daughters.

[c] Calculated using GEE to account for multiple members in one family.

[d] Relatives with breast cancer only or with multiple primary cancers including breast cancer.

[e] Relatives with at least one primary non-breast cancer.

[f] Relatives with cancer(s) at the site specified only or those with multiple primary cancers, including one at the site specified.

**Table 4.**

Predictors of sensitivity of female probands' reports of family history of breast cancer in female first-degree relatives [a] compared with cancer registry records, Northern California Breast Cancer Family Registry

| | Female first-degree relatives [b] with breast cancer in the California Cancer Registry | | | |
|---|---|---|---|---|
| | N | Also reported by probands | Sensitivity %, 95% CI) of proband report [c] | *P*-value [d] |
| All breast cancers | 551 | 526 | 95.5 (93.4–96.9) | 0.02 |
| *In situ* | 52 | 46 | 88.5 (76.6–94.7) | |
| Invasive | 499 | 480 | 96.2 (94.1–97.6) | |
| **Breast cancer** (*in situ* or invasive) | | | | |
| Proband's race/ethnicity [e] | | | | |
| Non-Hispanic white | 222 | 214 | 96.4 (93.0–98.2) | |
| Hispanic white | 113 | 103 | 91.2 (84.4–95.2) | 0.05 |
| African American | 116 | 113 | 97.4 (92.2–99.2) | 0.61[f] |
| Asian American | 98 | 94 | 95.6 (89.0–98.3) | 0.82 |
| Chinese | 35 | 33 | 94.3 (79.8–98.6) | 0.55 |
| Filipina | 37 | 36 | 97.3 (83.0–99.6) | 0.78 |
| Japanese | 19 | 19 | 100 | n/a |
| Other Asian/Pacific Islander | 7 | 6 | 64.1 (41.1–82.0) | 0.11 |
| Other | 2 | 2 | 100 | n/a |
| **Breast cancer** (invasive only) | | | | |
| Proband's race/ethnicity [e] | | | | |
| Non-Hispanic white | 198 | 193 | 97.5 (94.1–98.9) | |
| Hispanic white | 102 | 94 | 92.1 (85.0–96.0) | 0.04 |
| African American | 113 | 110 | 97.3 (92.0–99.1) | 0.94 |
| Asian American | 84 | 81 | 96.4 (89.5–98.8) | 0.63 |
| Chinese | 31 | 29 | 93.5 (77.6–98.4) | 0.25 |
| Filipina | 32 | 31 | 96.9 (80.7–99.6) | 0.84 |
| Japanese | 17 | 17 | 100 | n/a |
| Other Asian/Pacific Islander | 4 | 4 | 100 | n/a |
| Other | 2 | 2 | 100 | n/a |
| Proband's age (years) [g] | | | | |
| <50 | 186 | 180 | 96.8 (93.0–98.5) | 0.29 |
| ≥50 | 365 | 346 | 94.8 (92.0–96.6) | |
| Proband's education | | | | |
| High school graduate or less | 141 | 133 | 94.3 (89.1–97.1) | 0.45 |
| Some college or more | 410 | 393 | 95.9 (93.4–97.4) | |
| Proband's place of birth | | | | |
| U.S.-born | 444 | 427 | 96.2 (93.9–97.6) | 0.10 |
| Foreign-born | 107 | 99 | 92.0 (84.9–95.9) | |
| Hispanic whites | | | | |

| | Female first-degree relatives [b] with breast cancer in the California Cancer Registry | | | |
|---|---|---|---|---|
| | N | Also reported by probands | Sensitivity %, 95% CI) of proband report [c] | *P*-value [d] |
| U.S.-born | 77 | 71 | 92.1 (83.5–96.4) | 0.54 |
| Foreign-born | 36 | 32 | 88.4 (73.3–95.5) | |
| Chinese | | | | |
| U.S.-born | 12 | 12 | 100 | n/a |
| Foreign-born | 23 | 21 | 91.3 (71.1–97.8) | |
| Proband's English language proficiency | | | | |
| Spoken well | 514 | 494 | 96.1 (94.1–97.5) | <0.01 |
| Not spoken well | 33 | 28 | 80.0 (52.8–93.5) | |
| Hispanic whites | | | | |
| Spoken well | 92 | 86 | 93.4 (86.1–97.0) | 0.07 |
| Not spoken well | 21 | 17 | 78.8 (53.7–92.2) | |
| Chinese | | | | |
| Spoken well | 27 | 26 | 96.3 (77.9–99.5) | 0.37 |
| Not spoken well | 8 | 7 | 87.5 (46.3–98.3) | |

Abbreviation: CI, confidence interval.

[a] Probands could report multiple cancers for each relative in the family history questionnaire.

[b] Full and half-sisters, mothers, and affected adult daughters.

[c] Calculated using GEE to account for multiple members in one family

[d] Two-sided *P*-value from Wald test using empirical standard error.

[e] Race/ethnicity is self-reported based on the probands' screening interview. Given small counts for some racial/ethnic groups, we combined groups as follows: African Americans include Black Hispanics; Other Asian/Pacific Islanders includes Asian Hispanics; Other includes mixed race, Native Americans, and unspecified race/ethnicity.

[f] *P*-value for each racial/ethnic group compared with non-Hispanic whites.

[g] Age at questionnaire completion.

**Table 5.**

Female relatives' report of personal history of breast cancer compared with cancer registry records, Northern California site of the Breast Cancer Family Registry

| | Female first-degree relatives with cancer in the California Cancer Registry | | | | |
|---|---|---|---|---|---|
| | **Breast cancers identified in the cancer registry** | **Breast cancers also reported by relative** | **Sensitivity % (95% CI) [a] of relative report** | **Breast cancers also reported by proband** | **Sensitivity % (95% CI) [a] of proband report** |
| **All breast cancer** | 182 | 173 | 95.9 (91.9–98.0) | 156 | 86.2 (80.3–90.5) |
| *In situ* | 26 | 19 | 73.1 (53.5–86.6) | 15 | 57.7 (38.5–74.8) |
| Invasive | 156 | 154 | 98.7 (95.0–99.7) | 141 | 90.3 (84.6–94.1) |
| ***In situ* or invasive breast cancer** | | | | | |
| Relative's race/ethnicity [b] | | | | | |
| Non-Hispanic white | 58 | 57 | 98.3 (88.7–99.8) | 52 | 89.6 (78.7–95.3) |
| Hispanic white | 52 | 47 | 93.7 (83.9–97.7) | 40 | 78.6 (65.3–87.7) |
| African American | 37 | 35 | 94.5 (80.6–98.6) | 32 | 87.9 (42.0–94.5) |
| Asian American | 35 | 34 | 97.1 (82.1–99.6) | 32 | 90.5 (74.8–96.9) |
| **Invasive breast cancer** | | | | | |
| Relative's race/ethnicity [b] | | | | | |
| Non-Hispanic white | 49 | 49 | 100 | 45 | 91.8 (80.2–96.9) |
| Hispanic white | 46 | 45 | 97.8 (86.1–99.7) | 39 | 84.7 (71.2–92.5) |
| African American | 35 | 34 | 94.5 (82.3–99.6) | 32 | 91.4 (76.4–97.2) |
| Asian American | 26 | 26 | 100 | 25 | 96.1 (76.9–99.5) |

Abbreviation: CI, confidence interval.

[a] Calculated using GEE to account for multiple members in one family.

[b] Race/ethnicity is self-reported based on the relatives' risk factor questionnaire. Given small counts for some racial/ethnic groups, we combined groups as follows: African Americans include Black Hispanics; Asian Americans include Asian Hispanics.