A Comparative Survey of the Cancer Information Service with the Greater Bay Area Cancer Registry

By

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This paper is dedicated to my beloved sister, Ying Zhang, who has shown me the meaning of strength and courage through her fight with Myelodysplastic Syndromes (MDS). I love you, sis.

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Introduction and Background

Cancer has been recognized as a major health problem in the United States for many years and we hear a lot about cancer. The news media bombard us with headlines such as "No Way to Avoid Cancer-Causing Agents". Public service announcements on television educate us about the seven warning signs of cancer and urge us to examine our breasts, stop smoking, eat less fat and more fiber. All this information does not necessarily produce educated consumers. Instead, consumers are frequently confused and frustrated (Freimuth, 1989). The National Cancer Institute (NCI) recognizes this need for accurate, confidential cancer information and funded the Cancer Information Service (CIS).

The Cancer Information Service (CIS)

CIS was established in 1975 in response to the public health mandate in the National Cancer Act of 1971, with the goal to "give cancer patients and members of the public immediate access to the latest information on cancer" (Morra 1993a). It serves the entire country, Puerto Rico, and the U.S. Virgin Islands through nineteen regional offices, located at NCI-designated cancer centers and other health care institutions (Thomsen and Maat, 1998) (Appendix1a). As of 2000, CIS has reorganized into fourteen regions and the entire state of California became one region. The CIS uses two primary channels to communicate information on cancer: a toll-free telephone service (1-800-4-CANCER) to reach individuals and an outreach

program that works with established partner organizations to reach minority and underserved audiences. The program model is built on the approach to health communications developed by the NCI's Office of Cancer Communications, an approach which incorporates aspects of various communications models, theories, and practices (Arkin, 1989; Glanz & Rimer, 1995). Both the telephone service and the outreach program operate on the same principle, an aim to affect behavior change by motivating individuals to make personal health behavior changes and become informed health care consumers as they navigate the medical system, and by supporting organizations in their ability to deliver and implement health education programs effectively (Thomsen and Maat, 1998).

The CIS telephone service answers calls in English and Spanish and for the deaf it uses a TTY component. The Cancer Information Service staff provides thorough and personalized attention to each caller and answer questions about how to prevent cancer, how to quit smoking, symptoms and risk, diagnosis, current treatments, and research studies (Ward et al, 1998). All calls are confidential. In 1976 when it was founded, the CIS answered 47,000 calls per year. Today, the CIS responds to 500,000 calls annually, which totaled to over 8 million calls. Each day the CIS receives 2,000 calls about cancer (CIS website).

Early in the program development, a number of CIS regional offices recognized the importance of a national evaluation program. In Nov 1975, an Evaluation Task Force (ETF) was established consisting of NCI staff, several CIS regional office evaluation and program stiff, and outside consultants. It was charged with developing a national evaluation plan, beginning with defining a common data

set for documenting inquiries to the system. This was to be the first of several unsuccessful attempts between 1976 and 1982 to implement a national evaluation plan. The early years of program evaluation were characterized by each office doing largely what it wished or not with a few pieces of standardized data being kept by most offices and reported to NCI. No truly reliable national data existed to describe the overall program except, perhaps, the total number of inquiries and their type. In 1982, the renewed NCI contracts for the CIS offices contained a mandatory requirement for participation in a national evaluation. A three parts evaluation was put in place: a common inquiry documentation system called the Call Record Form (Appendix 1b); a user survey; and a quality control program (Freimuth, 1989).

To ensure accuracy and quality, all CIS staff must go through a standard national staff training and certification program, to reach a level of knowledge and skill appropriate for communicating complex and dynamic cancer information. Training topics include, but are not limited to, cancer biology and genetics, communication techniques, and the psycho-social dimensions of cancer. The telephone service utilizes a number of processes to ensure accuracy, consistency, and communication skills across the network, like call monitoring, onsite supervision, and a national test call program, the CIS Evaluation and Reporting System, or CISTERS (Thomsen and Maat, 1998).

Many studies have been conducted to characterize the users of CIS. These descriptive profiles of a typical CIS caller are highly consistent across studies and time and indicate that the vast majority of CIS callers are female, White/Anglo, with at least a high school education. Studies have shown repeatedly that low income,

minority populations underutilize the CIS, despite the fact that they are often at higher risk for certain cancers. Most studies report that 40-50% of the calls are from cancer patients or friends/relatives of cancer patients and fewer calls are from the general public. The majority of calls to the CIS have involved questions about cancer symptoms, diagnosis, and /or treatment. A relatively low percentage of calls have involved topics related to cancer prevention, and an even smaller percentage of calls have been concerned with cancer screening (Marcus et al, 1993).

The cancer registry

The cancer registry is a system to monitor all types of reportable malignancies diagnosed or treated in an institution or geographic area. There are two types of cancer registries, either hospital-based or population-based. In either type, the data are usually collected from medical records provided by hospitals, physicians, and other care facilities. All data collected on cancer patients are stored under secure conditions to ensure patient confidentiality.

In 1987, cancer reporting became mandatory throughout the state of California, as established by Assembly Bill 136. This legislation designated cancer as a reportable disease and created the statewide California Cancer Registry (CCR), which is composed of 10 regional registries (Appendix 3). The Greater Bay Area Cancer Registry (GBACR), located at the Northern California Cancer Center (NCCC), collects, manages, and analyzes data on all cancers occurring among residents of nine counties of the Greater Bay Area, which represent two of the ten

regional registries of CCR. The registries for the Santa Clara region (Monterey, San Benito, Santa Clara, and Santa Cruz) are referred to as the southern counties, or region 1. The registries for the San Francisco-Oakland region (Alameda, Contra Costa, Marin, San Francisco, and San Mateo) are referred to as the northern counties or region 8 (Appendix 4). Data from the GBACR are submitted quarterly to the CCR and are also submitted to the National Cancer Institute's Surveillance, Epidemiology and End Results (SEER) program annually to be compiled and analyzed further.

My Research Question

This study examines the telephone calls made to region 17 of CIS in both 1997 and 1998, and compares this information to the newly diagnosed cancer cases in 1996 as reported by the GBACR. Region 17 of CIS, which is also located at NCCC, receives calls from residents from northern California and Nevada (Appendix 1a). Over the years, the CIS has used a variety of tools to measure the satisfaction of its callers at a national level. Region 17 however has not done any analysis individually with its telephone call data. Therefore, the first part of this study is a descriptive analysis of the CIS Region 17 telephone data. This will be followed by the analysis of CIS utilization rate by using cancer cases recorded in the GBACR.

This is an exploratory study since there is no cited literature specifically dealing with CIS utilization among the cancer patients in the Greater Bay Area. The CIS and the GBACR at NCCC have never pooled their resources together, nor have studies been published comparing CIS phone calls with cancer incidences, either at a

regional or national level. In this cross-sectional study, by examining the call record and cancer incidence, I will aim to answer the question of how effectiveness is CIS meeting the needs of cancer patients? This analysis will help to identify specific groups, cancer sites, or geographic areas that appear to underutilize the CIS. This information can be used for program planning and evaluation purposes, allowing for future outreach programs targeting these underserved groups or areas.

Methods

Sample

All calls to the CIS telephone service in 1997 and 1998 have been documented on a standardized electronically coded record form (ECRF) (Appendix 1b). The ECRF codes important information on the type of caller, the subject of inquiry, the primary cancer site callers are concerned about, the response of the CIS information specialist to the caller, information resources used on the phone, whether the caller has called the CIS before, how the caller found out about the CIS, and demographic characteristics of the callers. The record form also records information on the time and the duration of the call, the time and the type of follow up action that is taken, and the primary language used during the call.

Procedures for Data Analysis

CIS data

The computer program SPSS 9.0 was used for analysis. Frequencies and cross tabulations were done on all variables. Due to the large amount of data, some of the variables were then collapsed into more general categories for analysis (Appendix 2). There were five variables that allowed for multiple responses: subject of inquiry, primary cancer site, response to caller, information resources used, and follow-up actions. Results are presented in the form of weighted percentages. Weights were required to adjust for caller's refusal to give information or hang ups, or specialist's failure to collect the information. Therefore "none applicable" cases were excluded in the analysis.

Cancer registry data

Cancer incidence data were based on new cases of primary cancer diagnosed in Region 1 and 8 residents between Jan 1 and Dec 31, 1996, and reported to the GBACR as of Nov, 1998. 1996 registry data was used because it was the latest available registry data at the start of this study due to the usual eleven months lag period between diagnosis and reporting to the registry. There is minimal variation of the registry data from year to year, therefore comparing CIS data from 1997 and 1998 with the 1996 registry data is valid (Personal Communication with Dee West).

A cancer case is defined as a primary malignant tumor, that is, one originating in a particular organ or anatomic site rather than having spread from another location. Primary site of the cancer have been coded according to the International

Classification of Diseases for Oncology (ICD-O), Second Edition, and sites have been grouped following the conventions of the SEER program. Registry data were presented for invasive cancers for each cancer site with the exception of bladder cancer, for which cancer incidence counts and rates are based on combined in situ and invasive cases.

The calls to cases ratio

A call to case ratio was constructed by dividing the number of CIS calls for a given gender, race/ethnicity, age group, cancer site, or county by the number of incident cases of cancer for that variable. The numerator includes the number of calls to the CIS made by all types of callers, patient and non-patients, and excludes calls that are not applicable. It must be made clear that the calls to cases ratio is not the actual utilization rate, but only an indicator. This study recognizes that there are many other ways to measure the utilization rate. The calls to cases ratio gives a rough utilization rate and is only useful for comparative or exploratory purposes.

For the purpose of this comparison, all CIS data used in the calls to cases ratio calculation was restricted to the nine counties covered by the GBACR. Otherwise, the CIS data includes all telephone calls from Region 17. Demographic data and cancer sites from the registry were also recoded into categories that were consistent with the CIS ECRF. It must be noted that for the registry, patients with Hispanic surnames were grouped as Hispanic, irrespective of whether they were white, black, or Asian/Pacific Islander. However, a caller with a Hispanic surname may identify oneself as belonging to another ethnic group instead of being Hispanic.

Results

I. Description of the entire CIS Region17 data: 1997-1998

A. Who were the callers?

Demographics

There were a total of 16,741 calls recorded for the year of 1997 and 18,360 calls for 1998 (Figure1). The demographic data of the callers from 1997 closely resembled those of 1998 (Table1). Females were much more likely to call than males, with a male to female ratio of 2.9:1 in 1997 and 2.6:1 in 1998 (Figure2). The gender disparity was consistent across age, race, education, and the type of caller. Whites made up an overwhelming majority of callers, 79.5% in 1997 and 76.2% in 1998 (Figure 3). Hispanic and Asian Pacific Islanders made up the next large groups of callers, but each less than 10%. African and Native Americans made up the smallest groups, combined they make up less than of 5% of the callers. Over 90% of the callers were between the age of 30 to 79, with its highest call volume from the age group 40-59 (Figure 4.1). Callers over 80 and younger than 30 made up less than 10%. The age mean in 1997 and 1998 also closely resembled each other, with 51.1 in 1997 and the standard deviation of 15.09, and 50.9 in 1998 with the standard deviation of 15.08 (Figure 4.2, 4.3). It must be noted that in 1997, only the age of every other caller was recorded. The well educated were also more likely to call than those with less education (Figure 5). More than 75% of the callers had some college education, less than 5% of the calls were from those who did not finish high school.

More than 2/3 of the calls was from those who had never called CIS before and almost all calls were in English, with a 97.9% in 1997 and 96.9% in 1998.

Type of Callers

Cancer patients made up more than 30% of the callers, while spouses, relatives, or friends made up 38.3% of the calls in 1997 and 37.1% in 1998 (Table 1). Professionals and the general public made up the next large groups of callers, 11.4% and 10.6% in 1997, 12.1% and 11.5% in 1998, respectively. 6.5% of the calls were from patients with symptoms of disease, but not diagnosed with cancer, and finally less than 2% of the calls were from spouses, relatives, or friends of patients with symptom, but not diagnosed with cancer.

How did the callers found out about CIS?

Most of the callers found out about CIS through a variety of resources: organizations, relatives or friends, NCI publications, phone books, media, or health professionals. There was not one particular resource that generated more than 15% of the calls (Table 1).

B. What did the callers wanted to know?

Subject of Inquiry

A high volume of callers asked for information on specific treatments, 38.0% in 1997 and 41.6% in 1998 (Table 2). Callers asking information regarding cancer sites

made up the next highest group, 18.2% in 1997 and 16.5% in 1998. Callers inquiring about support services, health professionals, each made up less than 10% of the calls, and callers asking information about psychosocial issues, screening and diagnosis, prevention or risk factors, different cancer related organizations, each made up less than 6% of the calls.

Primary Cancer Sites

Under the collapsed categories of primary cancer sites, callers were most likely to seek information in six categories, breast, GI/digestive system, lymphatic and circulatory system, male genital/reproductive system, respiratory/intrathoracic organs, and female genital/reproductive system (Table 2, Figure 6). Inquiry about breast cancer was significantly higher than any other cancer sites, 24.0% in 1997 and 25.8% in 1998. When looking at major specific cancer sites, lung, prostate, and colon cancers were also higher than other sites, they each made up more than 5% of the calls (Table 2, Figure 7).

C. How did CIS respond?

Only 1% of the time in 1997 and 0.3% in 1998 did the CIS information specialists fail to make a medical disclaimer when they should have (Table 3). More than 50% of the calls lasted less than 10 minutes, 30.6% of the calls lasted between 10 to 20 minutes, and 16% of the calls were longer than 20 minutes. (Note: duration of the calls were not available for the 1997 data). One of CIS's major responses to callers was to introduce behavioral suggestions, 51.2% in 1997 and 48.8% in 1998.

The next most common response was to provide referrals, either to the NCI, to the Health Professional, the community, or other resources. Less than 17% of CIS specialists responded by giving support, and less than 3.2% provided information only without making behavior suggestions, support, or referrals. More than half of the time specialists used either Physician Data Query (PDQ) or NCI publication as resources for information. Using a secondary resource such as CIS staff or textbooks, etc. made up 35.1% in 1997 and 36.0% in 1998. Majority of the follow up actions took place within five minutes after the call. Almost 46% of the time specialists followed up a call by sending callers PDQ publications regarding to the subject they inquired, 45.6% in 1997 and 44.4% in 1998. Mailing information made up almost 30% and not taking any follow up actions made up almost 23%. Less than 1% of the time did the information specialists made call backs or send letters.

II. Cancer incidence recorded in the GBACR

There were a total of 28,249 newly diagnosed cancer cases reported from the GBACR in 1996. The ratio of male to female cases was almost 1:1 (Table 4, Figure 8). In general, the age of those with newly diagnosed cancer as reported by the registry was older than the age of CIS callers, with its highest incidences occurring between the age of 60 to 79. Whites had the highest number of recorded cancer cases, 72.2%, and the APIs had the second highest number in the registry, 11.6%. Breast cancer, cancer of the GI/Digestive/Retroperitoneum system, the male reproductive system, and cancer of the respiratory/intrathoracic organ had the highest

number of cases than other sites, ranging from 13.2 to 18.7% of the total cancer cases recorded in the GBACR. Out of the four major cancer sites, breast cancer had the highest number of cases and colon cancer had the lowest number of cases, 18.3% vs. 7.6%, respectively. Santa Clara and Alameda counties had the greatest number of cancer cases, each making up more than 20% of the total number of cases recorded in the registry. Marin, Monterey, Santa Cruz, and San Benito had the lowest number of cases. It is important to keep in mind these percentages largely reflected the population of these counties.

III. Comparison of CIS phone calls with cancer incidences in the GBACR using Calls/Cases Ratios

A. Demographic Characteristics

The ratios of calls to cases were all below 1, which indicate more cancer cases than CIS phone calls. The overall calls to cases ratio is 0.20. Females utilize CIS much more than males, for the ratio of calls to cases was almost three times higher for females than male, 0.30 vs. 0.11 (Table 5, Figure 9). The ratios of calls to cases for White and Hispanic were highest among all ethnic groups, 0.21 and 0.20, respectively (Table 6, Figure 10). The ratio for API was 0.15, and the ratio for Blacks was the lowest, 0.11. It must be recognized that even though the ratio for Native Americans was 2.03, this ratio may be inflated due to the small number of cases.

In general, the age of those with newly diagnosed cancer as reported by the registry was older than the age of CIS callers (Table 7, Figure 11.2). The age groups

of 20-29 and 30-39 have the highest calls to cases ratios, with 0.91 and 0.72 respectively (Figure 11.1). These ratios again may be inflated due to the low number of cancer cases among young people. The age group of 40-49 has 0.42. The age groups 10-19 and 50-59 have similar rates, 0.24 and 0.25. Age group 60 and above has the lowest calls/cases ratio, with 80+ having the ratio of 0.02.

B. Cancer sites

Under the collapsed categories for primary cancer sites, cancer of the musculoskeletal system had the highest calls/cases ratio, 0.49 (Table 8). Cancers of the breast, CNS, lymphatic/circulatory system, female reproductive system make up the second highest groups of calls/cases ratios: 0.30, 0.30, 0.28, and 0.24, respectively. Cancers of the head/neck, respiratory system, gastrointestinal/digestive system, endocrine system, male reproductive system, skin, and eye made up the third group, with ratios ranging from 0.15 to 0.12. The kidney/urinary system had the lowest calls/cases ratio, 0.10. A closer look at the four major cancer sites showed that breast cancer had the highest calls/cases ratio, 0.3, almost twice as high as the other major cancer sites (Table 9, Figure 12.1). Colon and lung cancers had a ratio of 0.16 and 0.15, respectively. Prostate cancer had the lowest calls/cases ratio, 0.13. A scatter plot of cases by calls grouped by cancer sites showed a clear linear trend, and a Spearman's test showed a correlation of 0.933 (Figure 12.2). This indicates that in general, there are more CIS calls about cancer sites with the higher number of cases. There is a strong correlation between the volume of phone calls with the number of cancer cases, vs. cancer sites (Spearman's rho=0.933, alpha=0).

A closer look of the each major cancer sites by gender (Table 10.1, Figure 12.3)

revealed again that female consistently had a higher ratio than males. The ratio of 5.37 for breast cancer by males is clearly inflated due to the low number of breast cancer cases among males. There was no significant difference of subject of inquiry among the male and females callers. A breakdown of the major cancer site by race/ethnicity (Table 10.2, Figure 12.4) revealed that there is a high calls to cases ratio for breast cancer across race/ethnicity. Hispanic had an especially high ratio, 0.51. The ratio among other ethnic groups ranged from 0.24 to 0.28. African Americans consistently had lower calls to cases ratios across the different major site and White consistently had higher ratios.

C. Counties

Among the nine different counties in the GBACR, the ratios ranged from 0.13 to 0.37 (Table 11, Figure 13.1, 13.2). Monterey and Marin have the highest ratios, 0.37 and 0.25, respectively. Alameda and Santa Clara have the second highest ratios, 0.20 and 0.17, respectively. San Benito, San Mateo, and San Francisco all had the ratio of 0.15. Contra Costa and Santa Cruz had the lowest ratios, 0.14 and 0.13, respectively. A scatter plot of cases by calls grouped by county showed a clear linear trend, and a Spearman's test showed a correlation of 0.936, with alpha=0 (Figure 13.3). This indicates that in general, the geographic areas with a higher number of cancer incidences utilize CIS more. This is even true when taking into account the different population density in each geographic location. A scatterplot of the call to case ratios grouped by population density showed that Monterey and Marin again had the highest ratio, disproportionately to their population density (Figure 13.4).

A closer look of the calls to cases ratios for each county by gender (Table 12.1, Figure 13.5) revealed that the ratios for female were especially high for Monterey and Marin, 0.58 and 0.38, respectively. Calls to cases ratios by race/ethnicity showed high ratios across all ethnic groups for Marin and Monterey, especially for the Hispanic population, with 0.43 for Marin and 0.38 for Monterey (Table 12.2, Figure 13.6). The ratio for the White population in Monterey (0.41) was also significantly higher than the ratio of other groups. A breakdown of county by cancer site showed that breast cancer consistently had higher ratios across the nine counties, and again, Marin and Monterey consistently had higher ratios than other counties across major cancer site (Table 12.3, Figure 13.7).

Discussion

The strong correlation of calls to cases, whether grouped by county or by site, indicates that the calls do not occur in a random fashion. However, there is no method to correlate the phone calls to individual cancer cases. There are probably calls that were made in regard to patients who reside out of the caller's county, either in another county covered by the GBACR or outside of the nine counties covered entirely. There are probably also callers who were diagnosed outside of the Greater Bay Area and therefore are not recorded in the GBACR. It is reasonable to speculate that most non-

patient callers are calling regarding to an immediate family member who is diagnosed with cancer and who lives near the vicinity of the caller. Therefore, this study offers only a crude measure of utilization versus incidence, future studies could achieve more accuracy by doing post-CIS call interviewing to screen for non-resident calls or for the CIS to start recording area of residency for the person for which the caller is asking information.

Another limitation of the study is the general classification of Asian Pacific Islanders. It is well known that API includes diverse groups of people from the Far East Asia, such as China and Japan, and those from Southeast Asia, such as Vietnam and the Philippines, who may have more differences than similarities. Since the CIS ECRF does not make distinction between these groups, the results of this study cannot be used to distinguish different groups within the API population, which may have very diverse behavior in CIS utilization and cancer incidences.

Analysis of the telephone call data of CIS Region 17 showed close resemblance to the national CIS data. Callers are mainly female, White, well educated. Most of the callers are family or friends of the patient and are interested in seeking information in regards to treatment options. The consistency of callers across the country illustrates that CIS is not reaching out to a very diverse group of patients, since only callers with the associated characteristics of above seem to utilize the service.

The overall low calls to cases ratios taken together reveals that there is more cancer incidences than CIS phone calls, and a large number of people with cancer apparently never utilize the CIS. This indicates a need for enhanced general CIS

marketing. There are many reasons that one is not using the CIS. There may be a true lack of need, a lack of awareness of the service, or some other obstacles that are preventing people from using the service. The obstacles may include 1. the perception of no need or 2. there is the perception of need, but one does not feel comfortable using the service, either due to language, cultural, or other barriers.

In spite of the many promotions of the CIS, we have seen consistent patterns of underutilization by minorities and the less educated. The lack of minority callers to CIS may appear to reflect the fewer overall numbers of cancer patients belonging to minority groups, however this is clearly not the case as demonstrated by the low calls to cases ratios among minority groups. There is apparently a need for cancer information among these groups. However, it is not clear these consumers are not engaging in any information searches at all or are just not using the CIS as one of their information sources.

The results demonstrated that the CIS is doing a great job at reaching out to the Hispanic population, for it has reached a similar utilization rate as White. The success with this ethnic group could be due to the effect of bilingual and bicultural cancer information specialists, which eliminate both language and cultural barriers. The low calls to cases ratios for both API (0.15) and African Americans (0.11) indicate that more work needs to be done in reaching out to these two groups. It is expected that APIs underutilize CIS, especially due to the language barrier since CIS does not provide its service in any Asian languages. It is not clear why the African Americans have the lowest utilization rate since one would expect language to be less of a barrier among this group than the Hispanics or the APIs. This low rate of

utilization indicates that there must be other existing obstacles that are preventing the African Americans from utilizing the CIS. One of these obstacles could be the cultural barrier.

Most work of health communication stems from studies of the White population, therefore one must be keenly aware that what works for one culture may not work for another. Different ethnic groups have different information seeking behaviors (Ward, 1993), thus may respond to different methods of outreach. Minorities are usually associated with lower SES and have relative cancer survival rates of 10-15% below the US overall rate of approximately 50% (ACS report, 1985). Thus, it is vital to eliminate barriers of using CIS for minorities and the poor, because learning about treatment options and clinical trials may save their lives.

Examination of call to case ratios by site reveals wide variation of utilization. The result that females consistently have higher utilization rate than males across major cancer sites is consistent with the existing theory that females are usually the healthcare taker in the family. This is best illustrated by prostate and breast cancer. Even though there were no cases of prostate cancer among females, there were still 169 calls from females inquiring the subject, which is more than 50% of the number of calls from males. Breast cancer on the other hand, is mainly a cancer of females, yet it did not show the same trend as prostate cancer. The number of phone calls from males regarding to breast cancer was only about 10% of the number of calls from females regarding to the subject, which confirms that females seem to be the active health information seekers in the family.

In light of the recent wave of breast cancer awareness efforts and the

preponderance of female callers, it is not surprising that breast cancer had the highest calls to cases ratio. The utilization rate is high across race/ethnicity, which is an indication that the CIS is doing a great job at reaching out to minorities. Unfortunately, this trend is not consistent for other major cancer sites, and this is especially true for the African Americans. Except for breast cancer, the utilization rates among this group were again much lower than the other ethnic groups.

Examining calls to cases ratios of various counties, it is clear that Marin and Monterey utilize CIS much more than the other counties in the GBACR, this is true even after taking into account the population of the counties. Both Marin and Monterey had relative low number of cancer incidences, yet the relative numbers of phone calls were high, therefore producing the especially high utilization rates. At first glance, it is no surprise that Marin county had a high CIS utilization rate, due to its population of high education and economic status (Appendix 5). This is very consistent with the current literature that socioeconomic status (SES) has major ramifications on health resources, including accessibility, availability, utilization, quality, and continuity of health services, including state of the art cancer screening, detection, treatment, and rehabilitation. In addition, SES affects nutritional status and dietary patterns, educational level/attitude and awareness of cancer preventive concepts/behaviors (Baquet and Ringen, 1986). Even though this theory explains the high utilization rate of Marin very well, it does not explain the high rate of Monterey. Monterey, a county that has low social economic status is expected to have a low CIS utilization rate, yet it had the highest rate among all counties.

A more detailed analysis of the calls to cases ratios of Marin and Monterey

shed some light on this counter intuitive result. The main contributor to the high ratio in Marin is actually due to the Hispanic population. Considering the minimization of the language and cultural barriers for this group, it is not surprising that the Hispanic has a high calls to cases ratio. The high ratio in Monterey is due to high ratios among all ethnic groups, but especially in the Hispanic and the White population. It is not clear why there were such a high volume of Hispanic callers relative to the number of cancer cases in Marin and Monterey, but a future look into how these callers found out about CIS may provide some explanations. Personal communication with CIS's outreach program director did not reveal any special campaigns targeting the Hispanic population in Marin or Monterey.

Final conclusions/Recommendations

Minorities are the targets for numerous health information campaigns because low income and poorly educated individuals and minorities are frequently at higher risk for many health problems. Yet when these same campaigns are evaluated, these groups usually emerge as less exposed, less knowledgeable, and less likely to change their behaviors (Freimuth, 1989). The utilization gap is quite significant. We may not need more campaigns, what we may need is to change the way we are campaigning to make the outreach programs more effective.

The consistent low utilization rate for African Americans has clearly demonstrated that there is a lot of room for improvement of the current outreach program working with established partners designated by the NCI. To increase minority's motivation to acquire health information and to make the information functional for them, one must tailor the message in a culturally appropriate manner. For example, churches are an integral part of the African American community, therefore publicizing CIS through churches rather than established governmental agencies may be more effective for this ethnic group.

Minorities are usually associated with poor education and lower SES (Freimuth, 1989). Instead of using pamphlets or newspapers, a more effective way of reaching to the minorities may be advertising through popular ethnic TV programs in their own languages. This is especially true since television has been reported as the information source most frequently used by the poor (Arkin et al). However, the high cost of television advertisement may make this method not very feasible.

Learning from the success of outreach to the Hispanic population, a program that is much less expensive would be recruiting more bilingual and bicultural information specialist for the APIs and the African Americans. CIS only provides service in English and Spanish currently, therefore even if CIS increase awareness among the ethnic minorities, language barrier still presents a big problem among the APIs. Considering the large Cantonese and Filipino population in the Bay Area, CIS may consider expanding its service in Cantonese and Tagalong. To make the outreach efforts towards APIs and African Americans even more effective, it is essential to recruit bicultural information specialists, who have a understanding of these callers' ethnic backgrounds and therefore are equipped to provide culturally appropriate services. Misinformation or inappropriate services may lead to detrimental effects: such as causing delays in seeking care.

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Table 1: Demographic data of CIS Callers 1997-1998

Demographic Characteristics	1997		1998	
	Count	Percent	Count	Percent
Gender				
Male	4261	25.7	2315	27.6
Female	12291	74.3	6079	72.4
Race				
API	778	5.7	470	6.4
Black	543	3.9	262	3.6
Hispanic	996	7.2	663	9.0
Native American	116	0.8	82	1.1
White	10937	79.5	5621	76.2
Other/Mixed	379	2.8	279	3.8
Age				
<10	4	0	0	0
10-19	83	0.6	53	0.7
20-29	1040	7.5	517	7.0
30-39	2403	17.4	1230	16.7
40-49	3014	21.8	1709	23.1
50-59	2980	21.5	1579	21.4
60-69	2508	18.1	1335	18.1
70-79	1538	11.1	787	10.7
80+	263	1.9	176	2.4
Education				
Grade school	166	1.2	118	1.6
Some high school	460	3.3	229	3.1
High school graduate	2475	17.9	1433	19.5
Some college	4276	31.0	2187	29.7
College graduate	3823	27.7	2035	27.7
Post-graduate	2599	18.8	1352	18.4
Called before?				
Yes	4677	33.2	4792	30.6
No	9335	66.2	10771	68.8

Language Used				
English	16389	97.9	17792	96.9
Spanish	352	2.1	568	3.1
Caller Type				
Patient	5210	31.4	5668	31.3
Spouse, relative, friend of patient	6361	38.3	6706	37.1
Undiagnosed person with symptoms	1086	6.5	1171	6.5
Spouse, relative, friend of person with symptoms	298	1.8	279	1.5
General Public	1766	10.6	2085	11.5
Professionals	1895	11.4	2184	12.1
How did caller found out about CIS?				
Relative/Friend	1694	12.4	2024	13.2
Health Professional	1101	8.1	1150	7.5
Media	1247	9.1	1835	12.0
NCI Publication	1467	10.7	1523	10.0
Organizations	1752	12.8	1606	10.5
Phone Book	1432	10.5	1680	11.0
Other	4982	36.4	5464	35.8

Table 2: Subject of Inquiry 1997-1998

	1997		1998	
	count	Percent of responses	count	Percent of responses
Subject of Inquiry				
Organizations	1314	3.7	1406	3.7
Health Professionals	2585	7.2	2778	7.3
Support Services	3281	9.2	3748	9.9
Prevention/risk factors	1602	4.5	1579	4.2
Screening/diagnosis	1913	5.4	1872	4.9
Site information	6502	18.2	6247	16.5
Specific treatment information	13575	38.0	15759	41.6
Psychosocial Issues	2078	5.8	1386	3.7
Other	2906	8.1	3124	8.2
Primary cancer sites				
Aids related	12	0.1	13	0.1
Breast	4189	24.0	4913	25.8
GI/digestive	2004	11.5	2339	12.3
Endocrine/thyroid	179	1.0	167	0.9
Eye	21	0.1	19	0.1
Head/neck	370	2.1	346	1.8
Lymph/circulatory	1619	9.3	1496	7.9
Kidney/urinary	480	2.8	494	2.6
Musculo/CT/soft tissue	364	2.1	337	1.8
CNS	377	2.2	381	2.0
Female genital/reproductive	1268	7.3	1244	6.5
Male genital/reproductive	1586	9.1	1550	8.1
Skin	647	3.7	702	3.7
Respiratory/intrathoracic	1492	8.6	1613	8.5
Other	237	1.4	244	1.3
Not applicable	2582	14.8	3173	16.7
Major cancer sites				
Breast	4189	24.0	4913	25.8
Colon	916	5.3	1121	5.9
Prostate	1434	8.2	1418	7.5
Lung	1390	8.0	1525	8.0
Other sites	6916	39.7	6881	36.2

Table 3: CIS Responses 1997-1998

	1997		1998	
	Count	**Percent of responses**	**Count**	**Percent of responses**
Response to callers				
Behavioral suggestions	18548	51.2	19898	48.8
Information only	1158	3.2	1107	2.7
Gave support	5795	16.0	6850	16.8
Referrals	10530	29.1	12456	30.6
None appropriate	185	0.5	437	1.1
Resources used				
PDQ	8075	28.5	8481	27.4
NCI publication	8564	30.2	8989	29.1
Secondary resource	9947	35.1	11140	36.0
None appropriate	1770	6.2	2294	7.4
Follow-up actions				
None	5282	22.5	5993	22.8
Send publications	10708	45.6	11688	44.4
Mail PDQ info	6743	28.7	7271	27.6
Other	755	3.2	1353	5.2
Medical disclaimer				
Yes	13694	81.8	14067	76.6
No	164	1.0	55	0.3
Not applicable	2883	17.2	4238	23.1
Duration of calls				
0-5 min			4702	26.2
6-10 min			4855	27.1
11-15 min			3402	19.0
16-20 min	NA	NA	2090	11.6
21-25 min			1209	6.7
26-30 min			687	3.8
> 30 min			995	5.5
Time for FU				
None	5282	31.6	5993	32.6
1-5 min	10223	61.1	11284	61.5
6-10 min	1016	6.1	844	4.6
>10 min	220	1.3	239	1.3

Table 4: Cancer Incidence in the GBACR 1996

Table 4.1 Gender

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 Female	14412	51.0	51.0	51.0
	2 Male	13829	49.0	49.0	100.0
	Total	28241	100.0	100.0	
Missing	System	8	.0		
Total		28249	100.0		

Table 4.2 Age of Diagnosis

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	<10	158	.6	.6	.6
	10-19	133	.5	.5	1.0
	20-29	480	1.7	1.7	2.7
	30-39	1369	4.8	4.9	7.6
	40-49	3043	10.8	10.8	18.4
	50-59	4692	16.6	16.6	35.0
	60-69	6513	23.1	23.1	58.1
	70-79	7627	27.0	27.0	85.1
	80+	4211	14.9	14.9	100.0
	Total	28226	99.9	100.0	
Missing	System	23	.1		
Total		28249	100.0		

Table 4.3 Race/Ethnicity

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	10 Asian/Pacific Islander	3132	11.1	11.6	11.6
	20 Black/African American (not of Hispanic origin)	2013	7.1	7.5	19.0
	30 Hispanic	2351	8.3	8.7	27.7
	40 American Indian/Alaskan Native	18	.1	.1	27.8
	50 White (not of Hispanic origin)	19492	69.0	72.2	100.0
	60 Other/Mixed (not of Hispanic origin)	9	.0	.0	100.0
	Total	27015	95.6	100.0	
Missing	System	1234	4.4		
Total		28249	100.0		

Table 4.4 Primary Cancer Site of Diagnosis

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Breast	5171	18.3	18.3	18.3
	GI/Digestive/ Retroperitoneum	5294	18.7	18.7	37.0
	Endo/Thyroid	426	1.5	1.5	38.6
	Eye	72	.3	.3	38.8
	Head/Face/Neck	818	2.9	2.9	41.7
	Lymph/Circulatory	1883	6.7	6.7	48.4
	Kidney/Urinary	1614	5.7	5.7	54.1
	Musculo/CT/Soft Tissue	245	.9	.9	55.0
	CNS	432	1.5	1.5	56.5
	Female Reproductive	1854	6.6	6.6	63.0
	Male Reproductive	4032	14.3	14.3	77.3
	Skin	1994	7.1	7.1	84.4
	Resp/Intrathoracic organ	3722	13.2	13.2	97.6
	Unknown	692	2.4	2.4	100.0
	Total	28249	100.0	100.0	

Table 4.5 Major Site of Diagnosis

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Other Sites	13760	48.7	48.7	48.7
	05 Breast	5171	18.3	18.3	67.0
	08 Colon	2154	7.6	7.6	74.6
	50 Prostate	3821	13.5	13.5	88.2
	60 Lung	3343	11.8	11.8	100.0
	Total	28249	100.0	100.0	

Table 4.6 County

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1 Alameda	5639	20.0	20.0	20.0
	7 Contra Costa	4291	15.2	15.2	35.2
	21 Marin	1503	5.3	5.3	40.5
	27 Monterey	1493	5.3	5.3	45.8
	35 San Benito	141	.5	.5	46.3
	38 San Francisco	4354	15.4	15.4	61.7
	41 San Mateo	3496	12.4	12.4	74.0
	43 Santa Clara	6284	22.2	22.2	96.3
	44 Santa Cruz	1048	3.7	3.7	100.0
	Total	28249	100.0	100.0	

Table 5: Ratios of Calls/Cases by Gender

Gender	Calls	% Calls	Cases	% Cases	Calls/Cases
Male	1497	26.0	13829	49.0	.11
Female	4292	74.0	14412	51.0	.30
Total	5789	100.0	28241	100.0	.20

Table 6: Ratios of Calls/Cases by Race/Ethnicity

Race/Ethnicity	Calls	% Calls	Cases	% Cases	Calls/Cases
Asian Pacific Islanders	477	9.0	3132	11.6	.15
Black/African American	223	4.0	2013	7.5	.11
Hispanic	462	8.7	2351	8.7	.20
Native American	37	.7	18	.1	2.03
White	4090	74.3	19492	72.2	.21

Table 7: Ratios of Calls/Cases by Age

Age	Calls	% Calls	Cases	% Cases	Calls/Cases
<10	1	.0	158	.6	.00
10-19	33	.6	133	.5	.24
20-29	437	7.9	480	1.7	.91
30-39	984	17.6	1369	4.9	.72
40-49	1275	23.5	3043	10.8	.42
50-59	1171	21.3	4692	16.6	.25
60-69	948	17.4	6513	23.1	.15
70-79	534	5.4	7627	27.0	.07
80+	98	1.9	4211	14.9	.02

Table 8: Ratios of Calls/Cases by Primary Cancer Site

Cancer Site	Calls	% Calls	Cases	% Cases	Calls/Cases
Breast	1532	29.4	5171	18.3	.30
GI/digestive	762	14.7	5294	18.7	.14
Endo/Thyroid	59	1.2	426	1.5	.14
Eye	9	.2	72	.3	.12
Head/Neck	120	2.2	818	2.9	.15
Lymph/Circulatory	536	10.0	1883	6.7	.28
Kidney/Urinary	159	3.0	1614	5.7	.10
Musculoskeletal/CT /Soft Tissue	119	2.2	245	.9	.49
CNS	131	2.5	432	1.5	.30
Female Repro	451	8.5	1854	6.6	.24
Mal Repro	543	10.1	4032	14.3	.13
Skin	234	4.5	1994	7.1	.12
Respiratory	524	10.1	3722	13.2	.14
Other	88	1.7	692	2.4	.13

Table 9: Ratios of Calls/Cases by Major Site

Cancer Sites	Calls	% Calls	Cases	% Cases	Calls/Cases
Breast	1532	29.4	5171	18.3	.30
Colon	345	6.7	2154	7.6	.16
Prostate	492	9.3	3821	13.5	.13
Lung	485	9.3	3343	11.8	.15

Table 10.1 Calls/Cases Ratios of Major Site by Gender

Cancer Site	Male			Female		
	Calls	Cases	Calls/Cases	Calls	Cases	Calls/Cases
Breast	161	30	5.37	1423	5141	.28
Colon	125	1035	.12	236	1118	.21
Prostate	313	3821	.08	169	0	NA
Lung	141	1797	.08	351	1546	.23

Table 10.2 Calls/Cases Ratios of Major Site by Race/Ethnicity

Cancer Site	Asian			Black			Hispanic			Native American			White		
	Calls	Cases	Calls/ Cases	Calls	Cases	Calls/ Cases	Calls	Cases	Calls/ Cases	Calls	Cases	Calls/ Cases	Calls	Cases	Calls/ Cases
Breast	140	573	.24	75	299	.25	190	371	.51	7	4	1.75	1046	3768	.28
Colon	39	269	.14	10	162	.06	17	165	.11	3	2	1.50	267	1525	.18
Prostate	31	326	.10	22	394	.06	27	286	.09	2	0	NA	364	2473	.15
Lung	39	372	.10	15	298	.05	20	195	.10	4	1	4.00	377	2438	.15

Table 11: Ratios of Calls/Cases by County

County	Calls	% Calls	Cases	% Cases	Calls/Cases
Alameda	1116	22.1	5639	20.0	.20
Contra Costa	601	11.9	4291	15.2	.14
Marin	369	7.3	1503	5.3	.25
Monterey	550	10.9	1493	5.3	.37
San Benito	21	0.4	141	.5	.15
San Francisco	658	13.0	4354	15.4	.15
San Mateo	529	10.5	3496	12.4	.15
Santa Clara	1074	21.3	6284	22.2	.17
Santa Cruz	132	2.6	1048	3.7	.13

Table 12.1: Calls/Cases Ratios of County by Gender

County	Male			Female		
	Calls	Cases	Calls/Cases	Calls	Cases	Calls/Cases
Alameda	284	2675	.11	856	2962	.29
Contra Costa	140	2045	.07	502	2243	.22
Marin	95	741	.13	287	762	.38
Monterey	122	744	.16	437	749	.58
San Benito	6	56	.10	17	85	.20
San Francisco	208	2355	.09	455	1997	.23
San Mateo	158	1653	.10	383	1843	.21
Santa Clara	306	3058	.10	807	3225	.25
Santa Cruz	36	502	.07	101	546	.18

Table 12.2: Calls/Cases Ratios of County by Race/Ethnicity

County	Asian			Black			Hispanic			Native American			White		
	Calls	Cases	Calls/ Cases	Calls	Cases	Calls/ Cases	Calls	Cases	Calls/ Cases	Calls	Cases	Calls/ Cases	Calls	Cases	Calls/ Cases
Alameda	112	590	.19	84	902	.09	78	482	.16	4	2	2.00	779	3411	.23
Contra Costa	42	276	.15	18	274	.06	42	230	.18	4	4	1.00	497	3365	.15
Marin	8	38	.21	3	25	.12	19	44	.43	2	0	NA	314	1330	.24
Monterey	18	91	.20	12	45	.26	73	191	.38	3	0	NA	424	1031	.41
San Benito	0	3	0	0	0	NA	3	34	.07	0	0	NA	18	100	.18
San Francisco	79	935	.08	33	488	.07	53	339	.15	3	5	.60	430	2489	.17
San Mateo	57	365	.16	16	150	.11	43	275	.16	6	4	1.38	380	2585	.15
Santa Clara	118	810	.15	24	124	.19	89	687	.13	8	3	2.67	784	4343	.18
Santa Cruz	2	24	.06	3	5	.50	0	69	0	2	0	NA	123	838	.15

Table 12.3: Calls/Cases Ratios of County by Major Site

County	Breast			Colon			Prostate			Lung		
	Calls	Cases	Calls/ Cases	Calls	Cases	Calls/ Cases	Calls	Cases	Calls/ Cases	Calls	Cases	Calls/ Cases
Alameda	384	1014	.38	70	427	.17	101	711	.14	106	739	.14
Contra Costa	195	838	.23	42	330	.13	56	602	.09	61	528	.12
Marin	106	302	.35	27	80	.34	43	250	.17	31	123	.25
Monterey	168	255	.66	27	88	.31	51	226	.23	43	189	.23
San Benito	5	36	.14	0	15	0	1	17	.09	2	10	.25
San Francisco	211	651	.32	44	355	.13	71	606	.12	64	507	.13
San Mateo	156	700	.22	39	304	.13	56	459	.12	52	412	.13
Santa Clara	321	1189	.27	97	464	.21	105	784	.13	107	720	.15
Santa Cruz	37	186	.20	13	91	.15	6	166	.04	13	115	.12

Figure 1: CIS Call Data 1997-1998

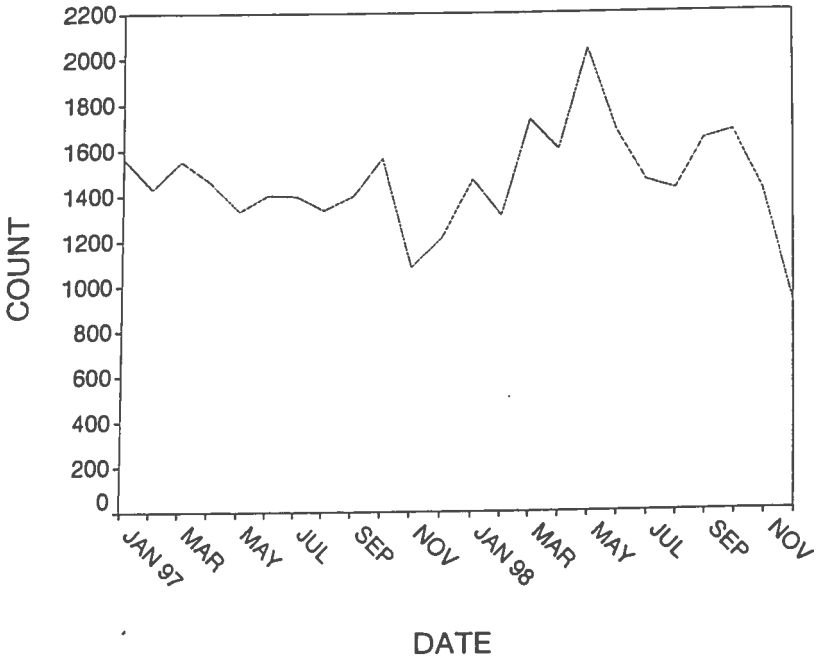


Figure 2: GENDER of CIS CALLERS

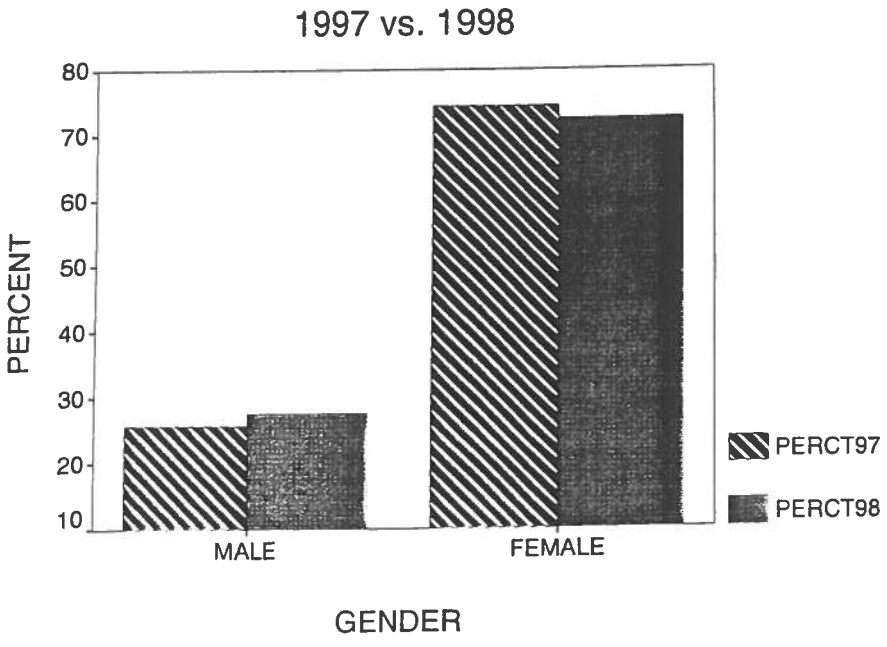


Figure 3: RACE/ETHNICITY of CIS CALLERS

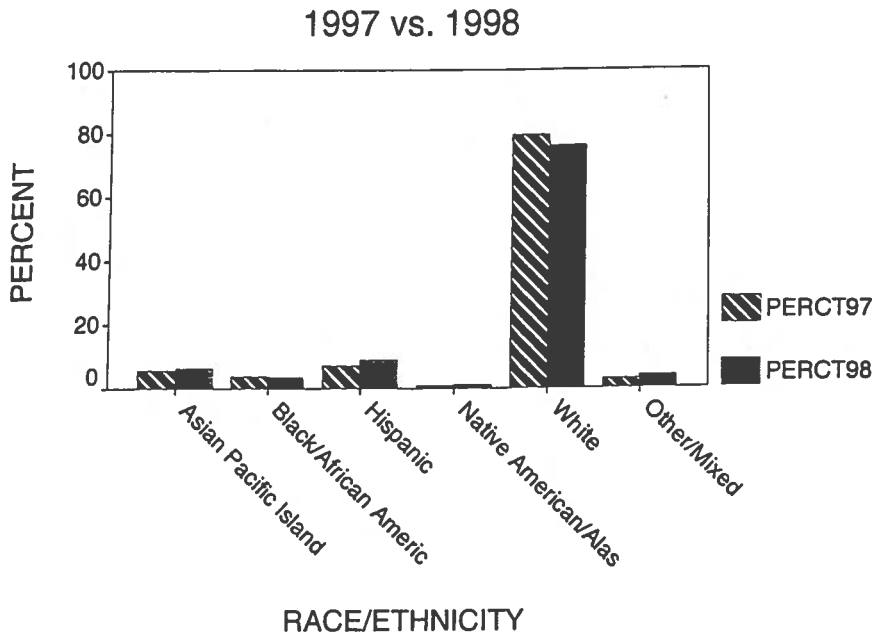


Figure 4.1: AGE of CIS CALLERS

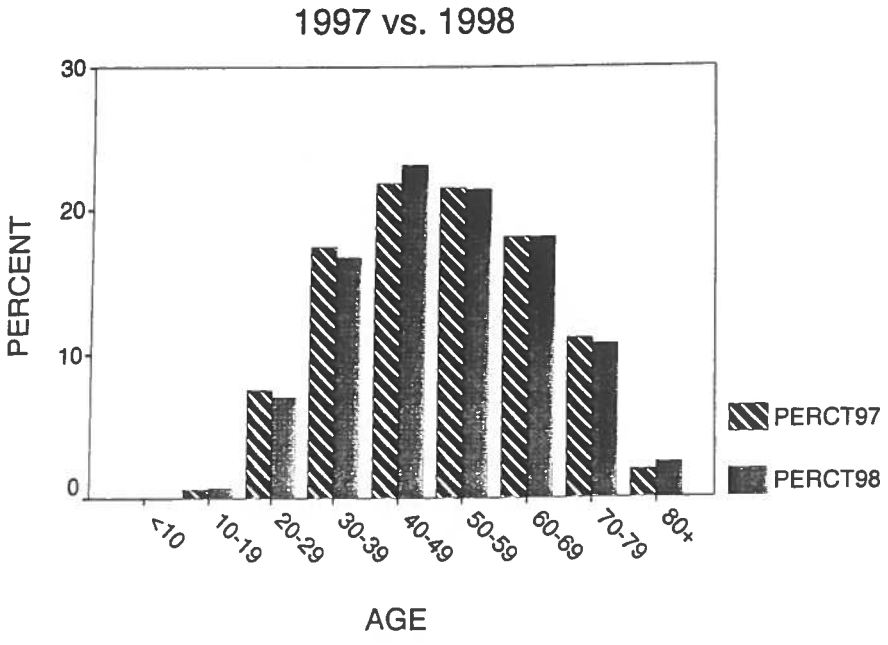
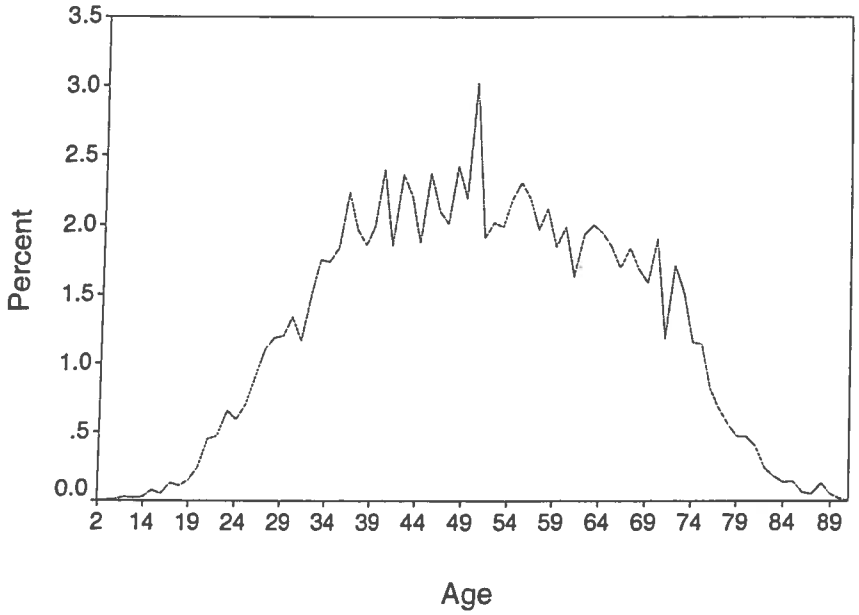


Fig 4.2: Age Distribution of CIS Callers 1997



N=7386 Mean=51.1 S.D.=15.9

Fig 4.3: Age Distribution of CIS Callers 1998

N=13833 Mean=50.9 S.D.=15.8

Figure 5: EDUCATION of CIS CALLERS

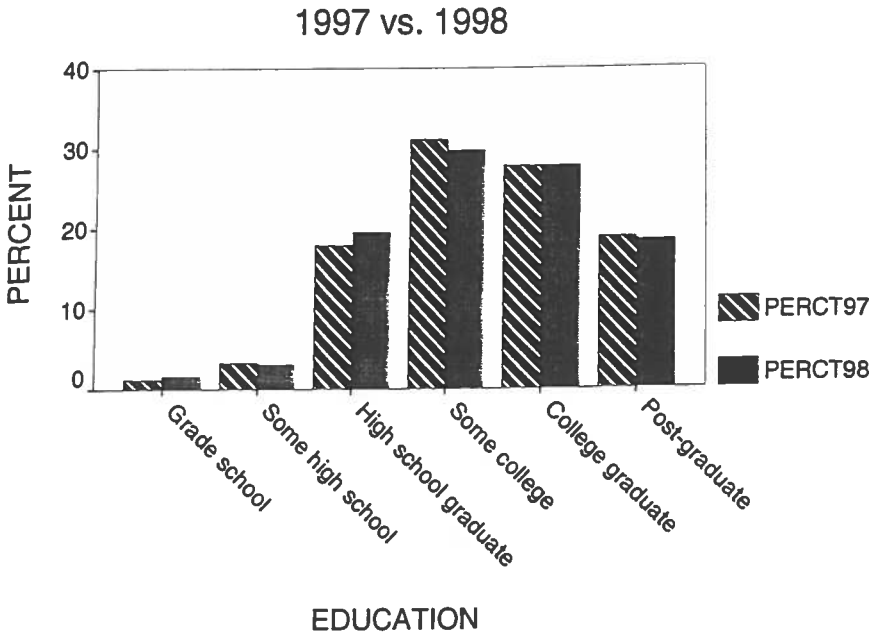


Figure 6: PRIMARY CANCER SITE

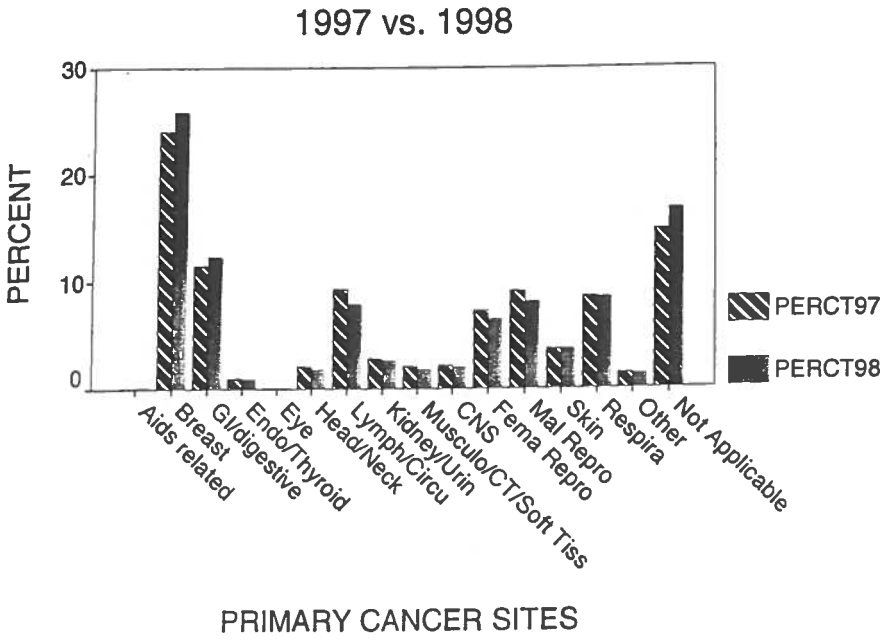


Figure 7: MAJOR CANCER SITE

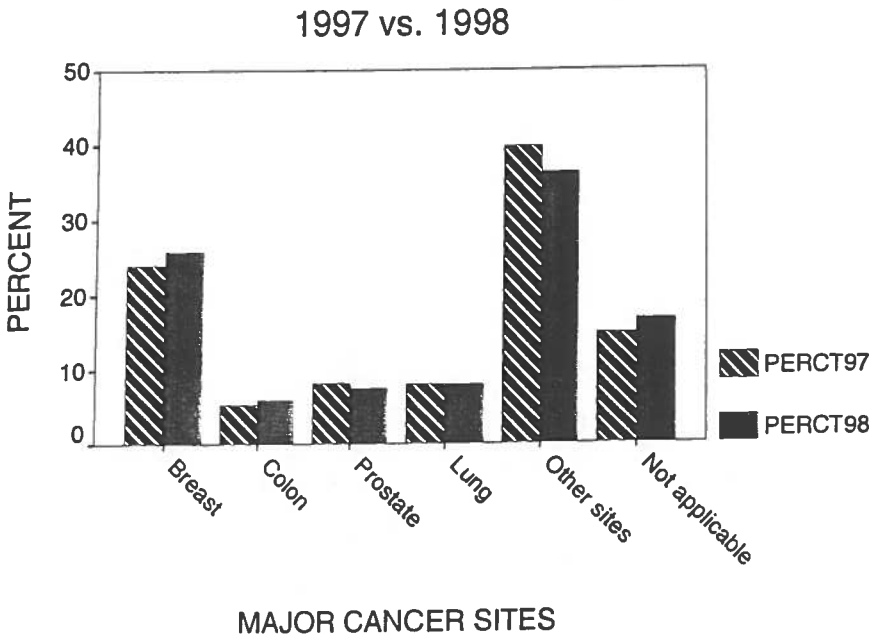


Figure 8: Description of Cancer Incidences in the GBACR 1996

Figure 8.1 Gender

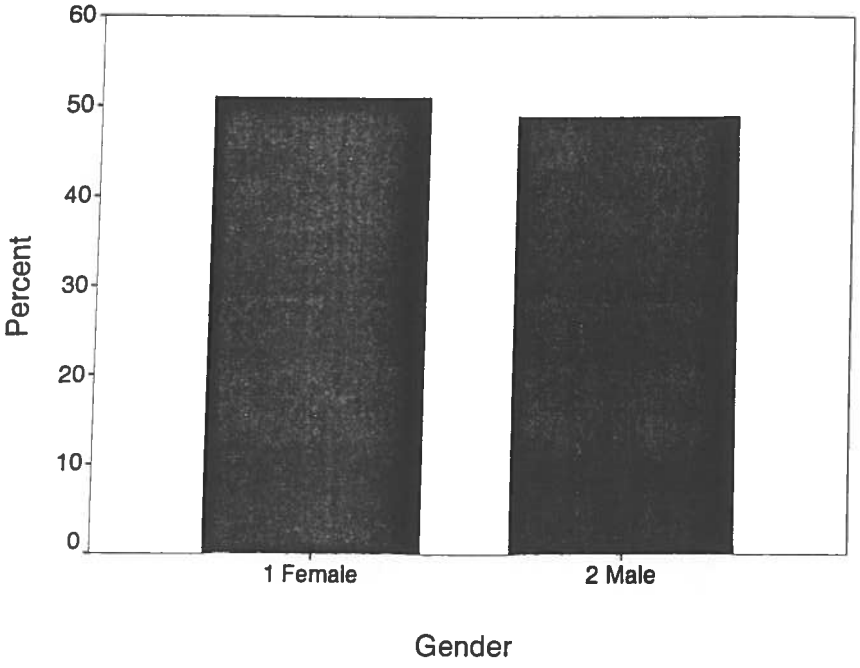


Figure 8.2 Age

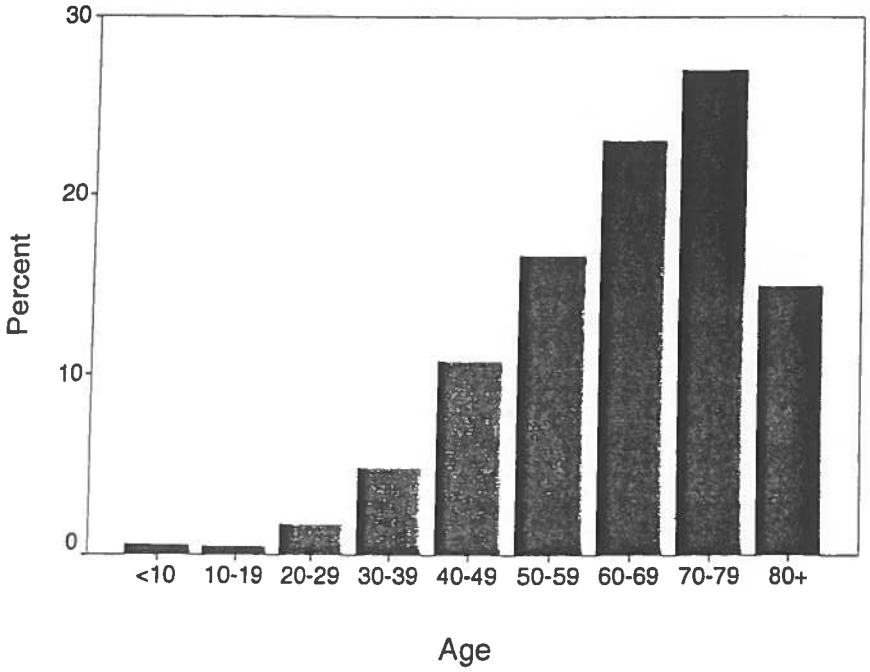
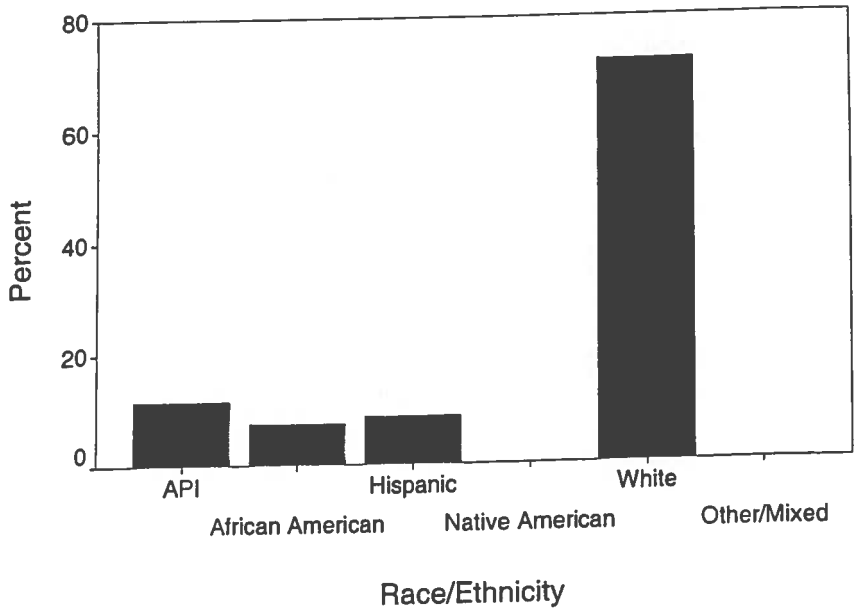


Figure 8.3 Race/Ethnicity



African American and White are not of Hispanic origins

Figure 8.4 Primary Cancer Site of Diagnosis

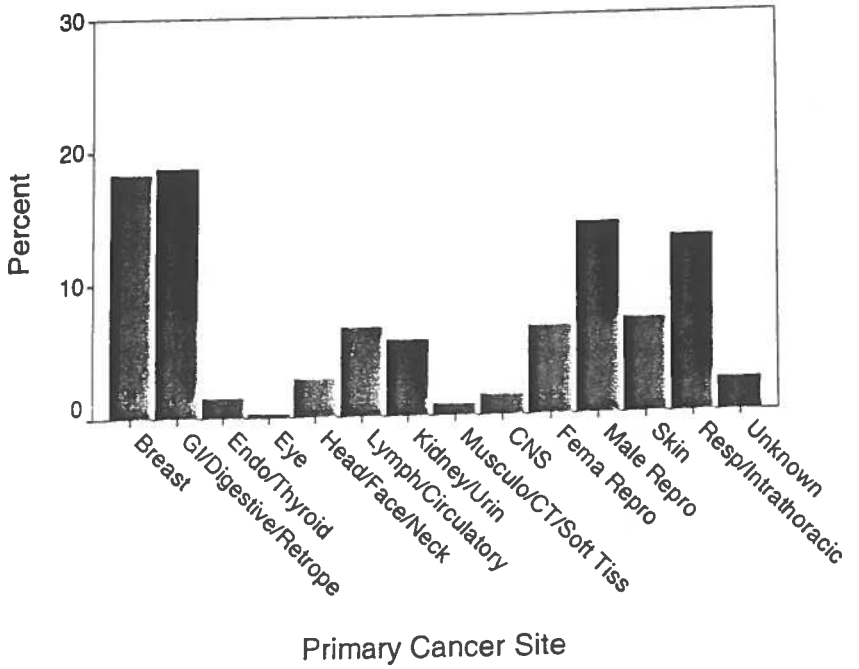


Figure 8.5 Major Site of Diagnosis

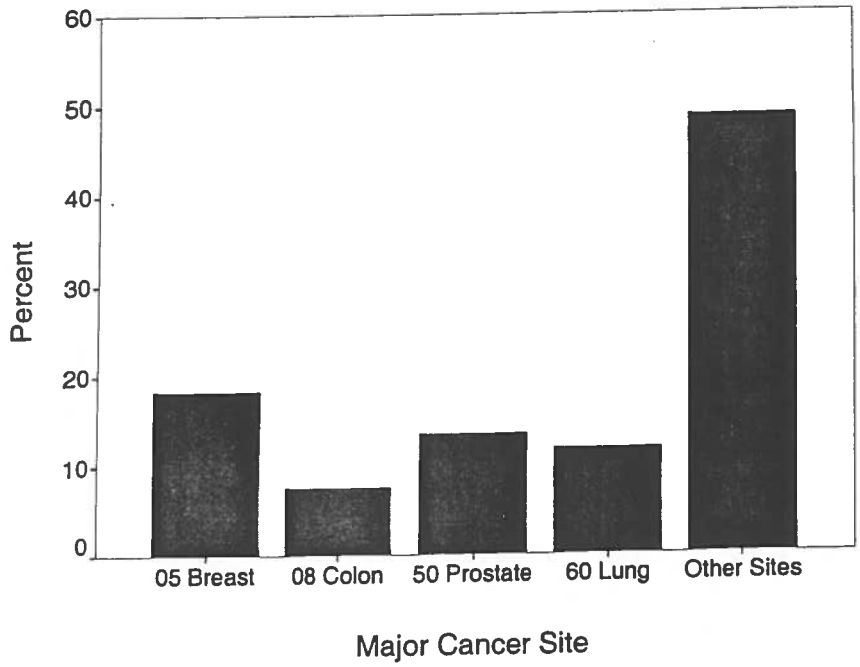


Figure 8.6 County

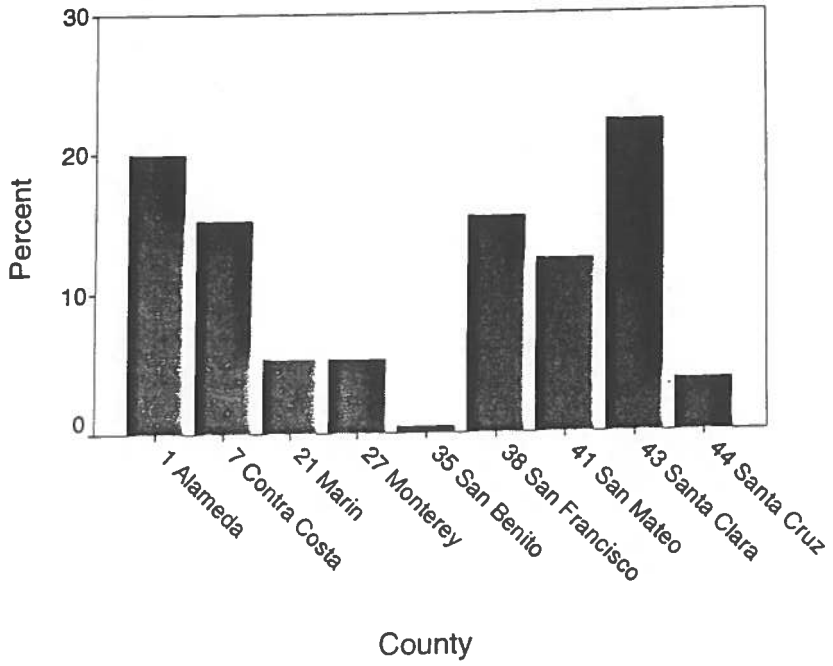


Fig: 9 Ratios of Calls/Cases by Gender

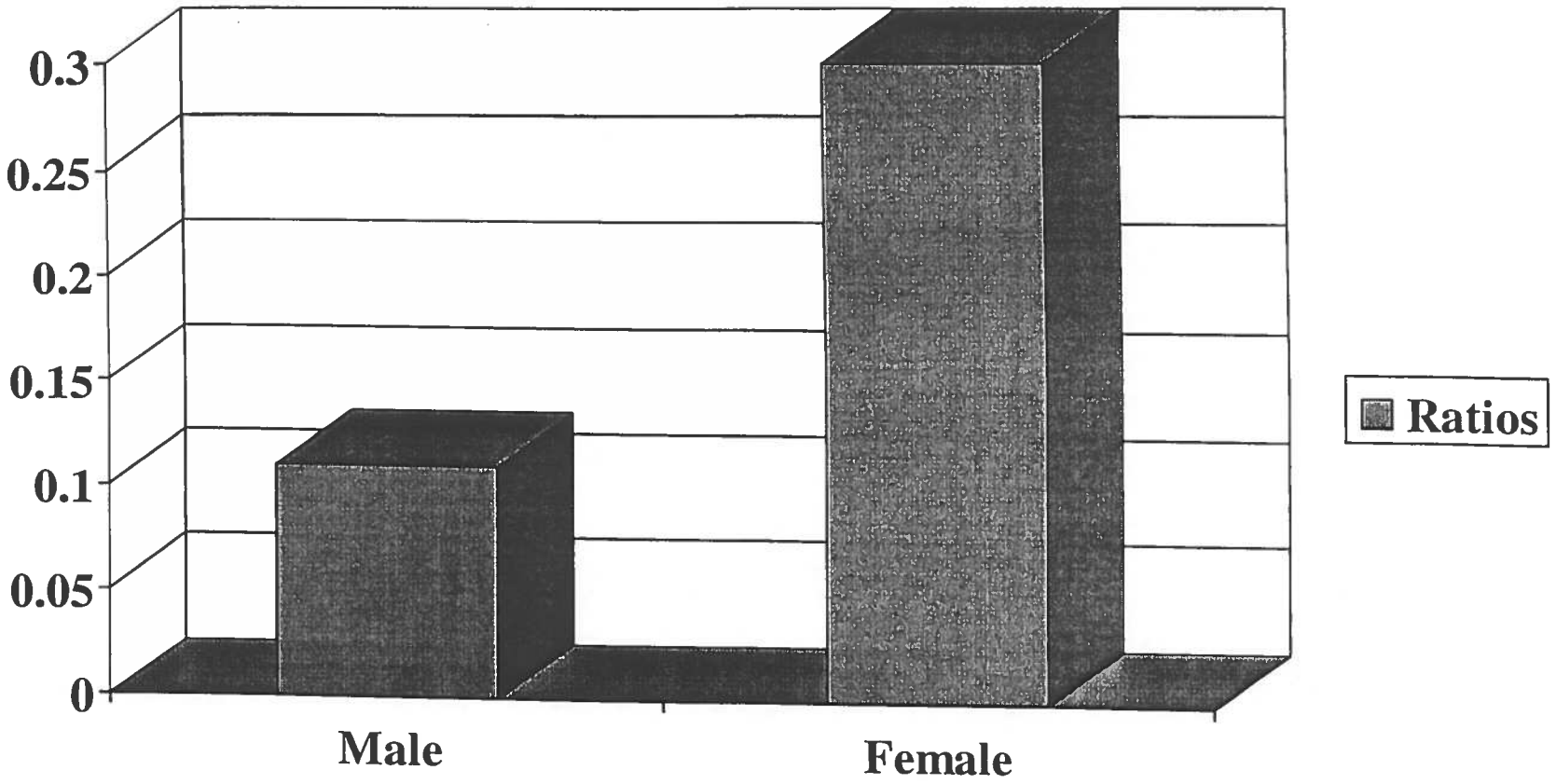


Fig 10: Ratios of Calls/Cases by Ethnicity

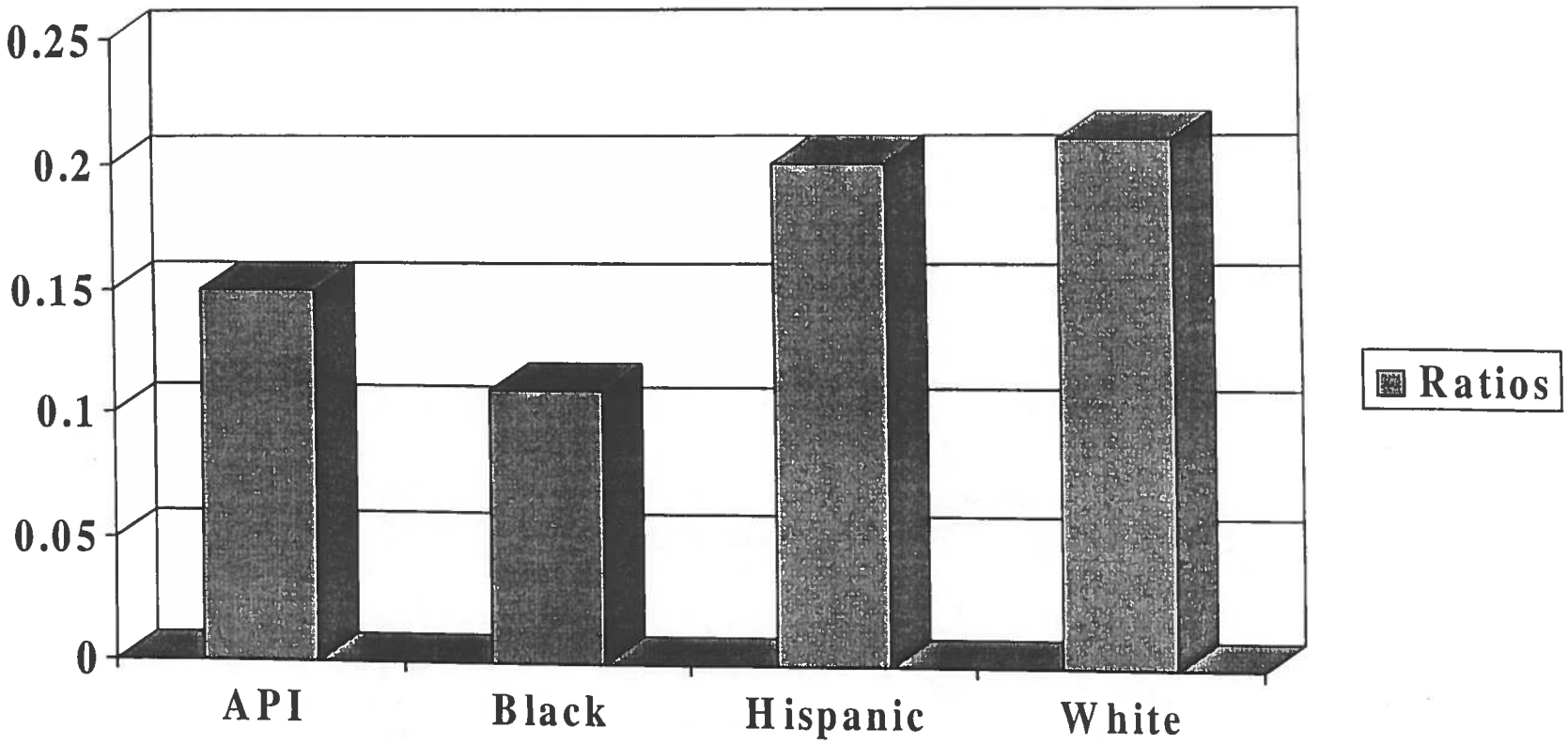


Fig 11.1 Ratios of Calls/Cases by Age

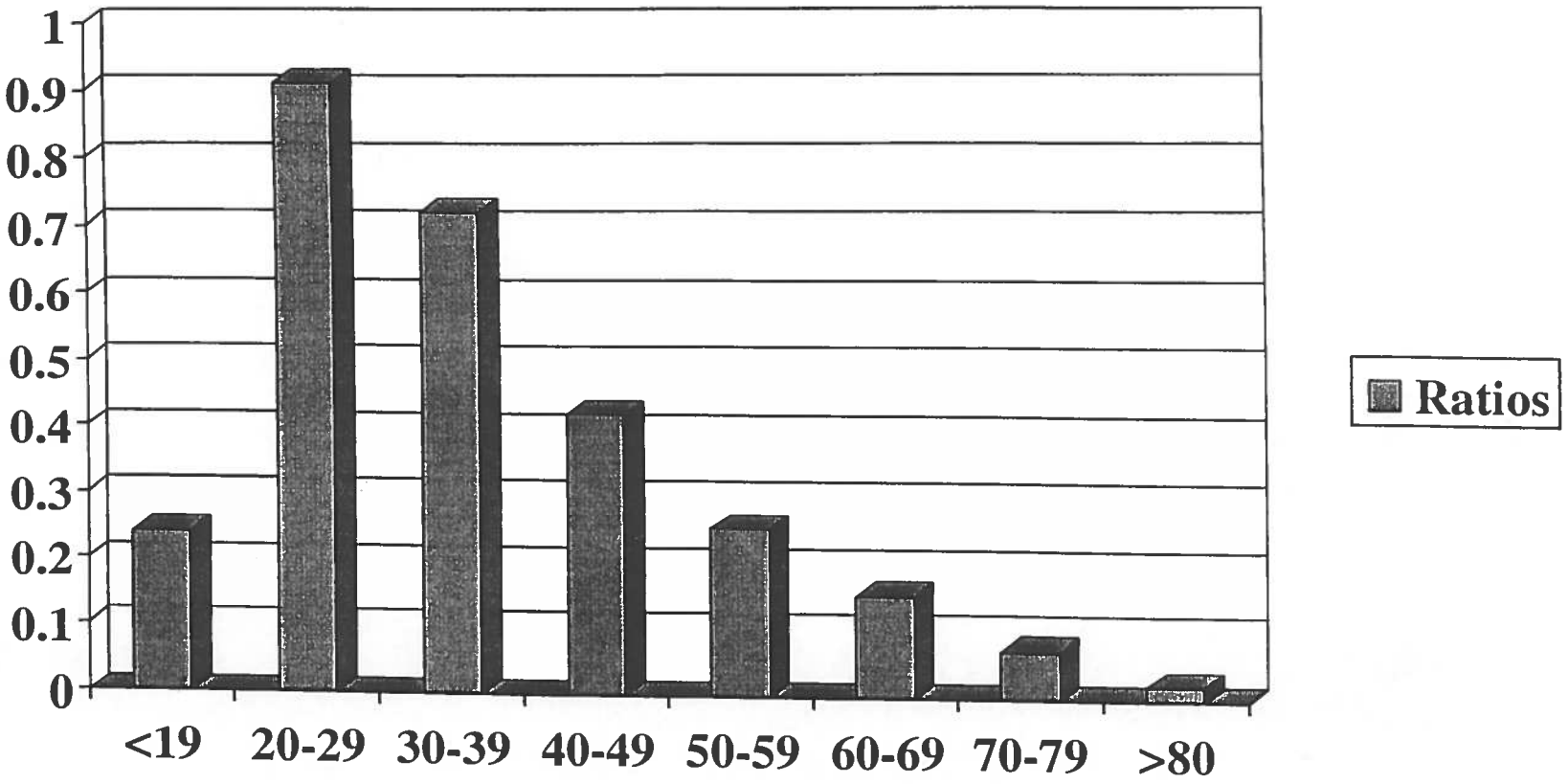
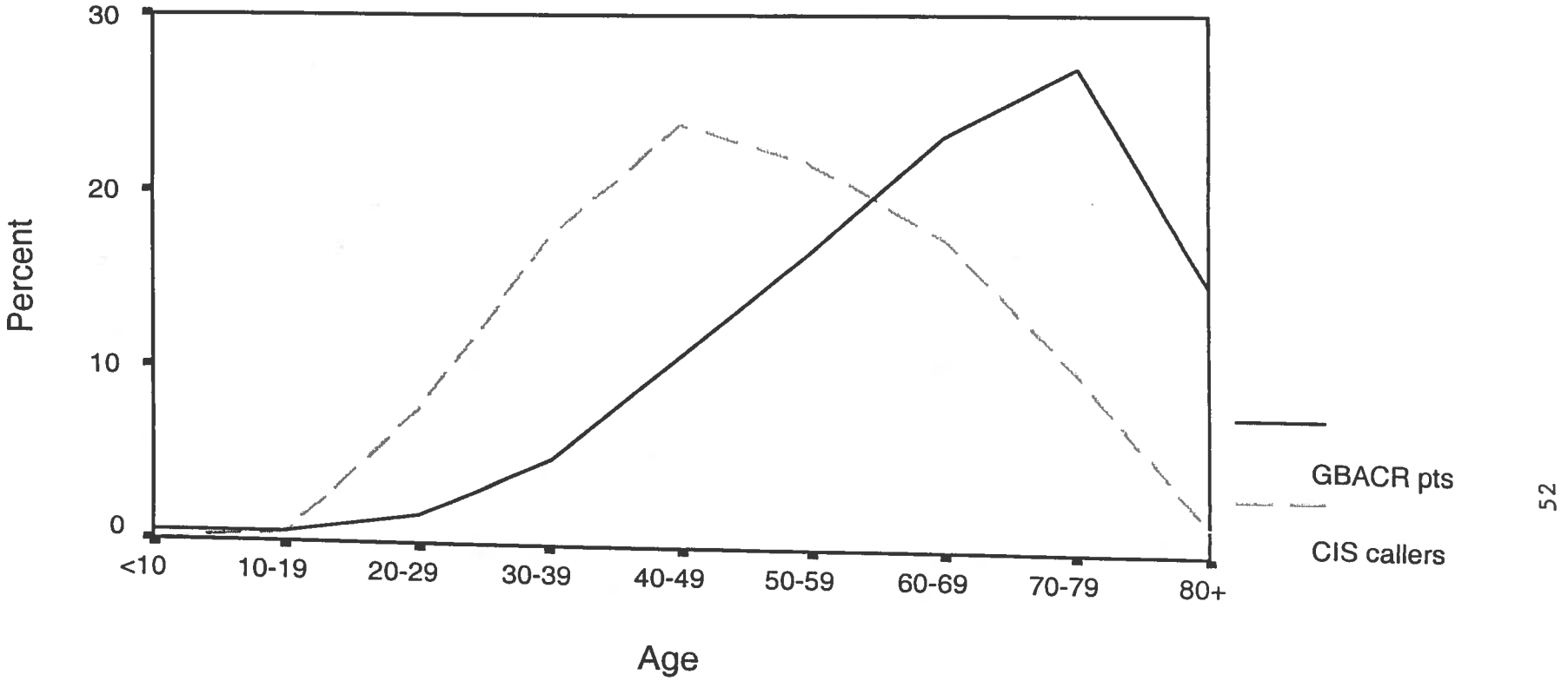


Fig 11.2: Age: Callers vs. Cases



CIS data excludes N/A cancer sites & callers, and were restricted to the 9 counties in the GBACR for the purpose of this comparison

Fig 12.1 Ratios of Calls/Cases by Sites

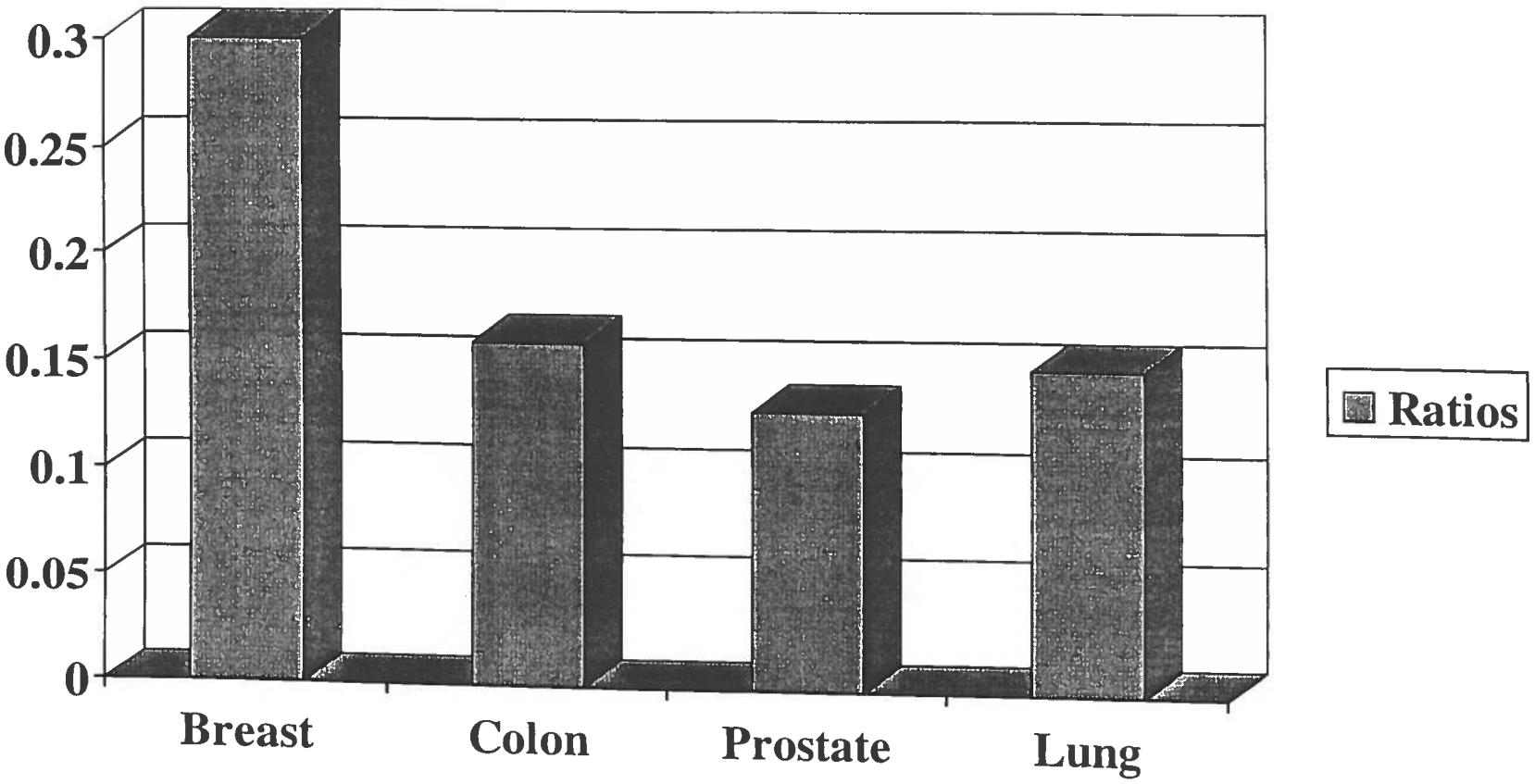


Fig 12.2: Plot of Calls by Cases: by sites

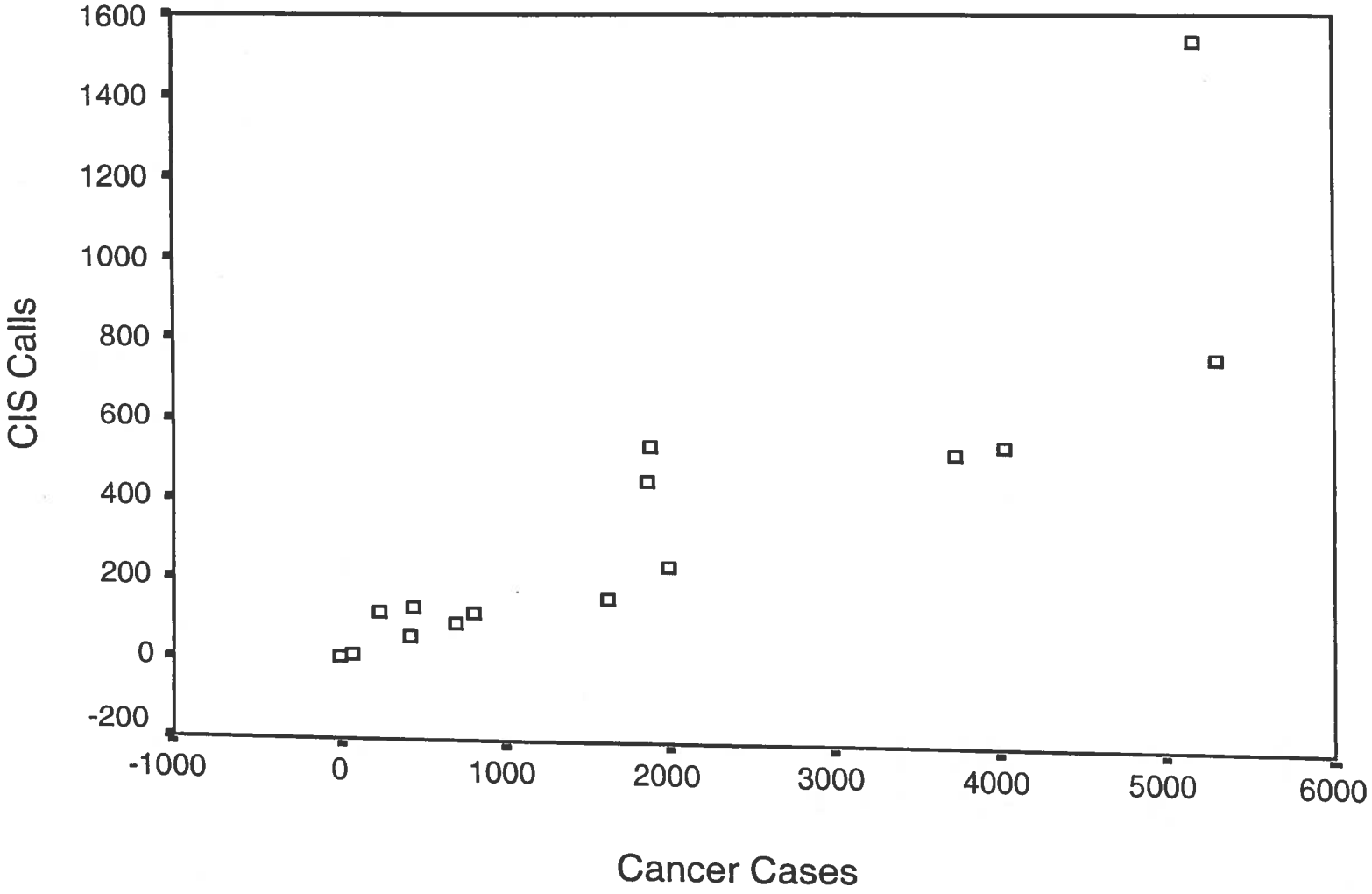


Fig 12.3: Ratios of Site by Gender

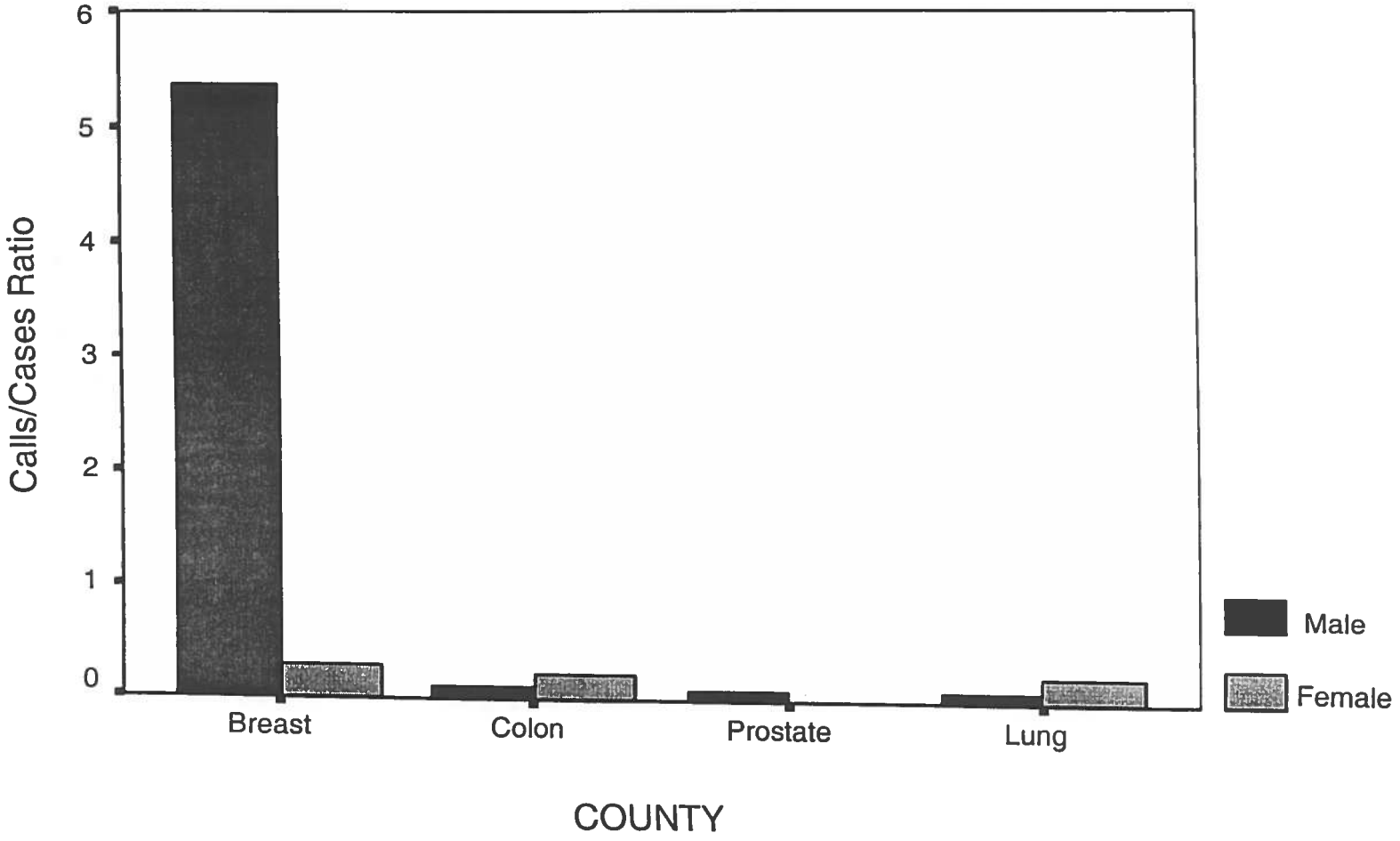


Fig 12.4: Ratios of Site by Race/Ethni

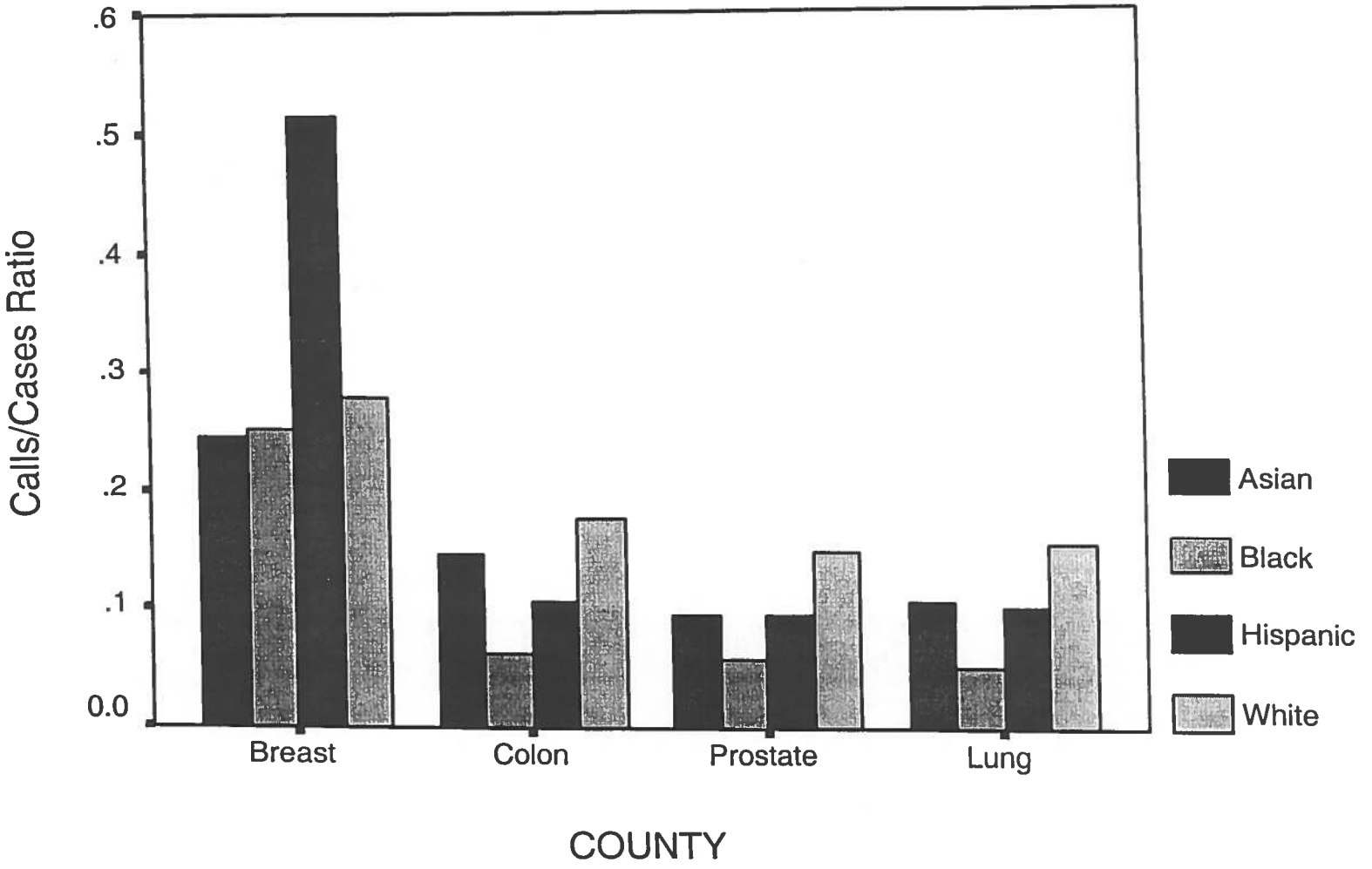


Fig 13.1 Ratios of Call/Case by County

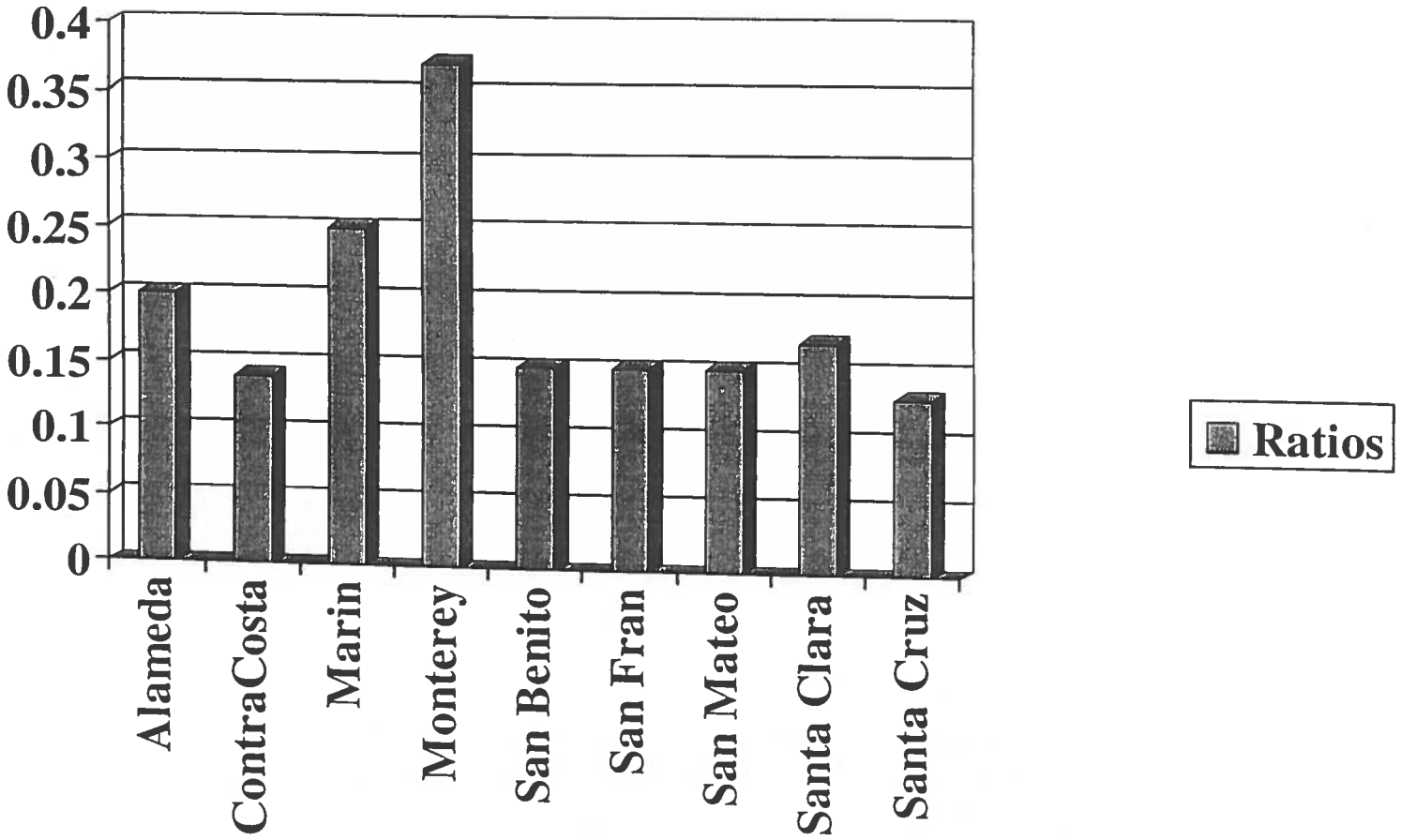


Fig 13.2 **Ratios of Calls/Cases by County**

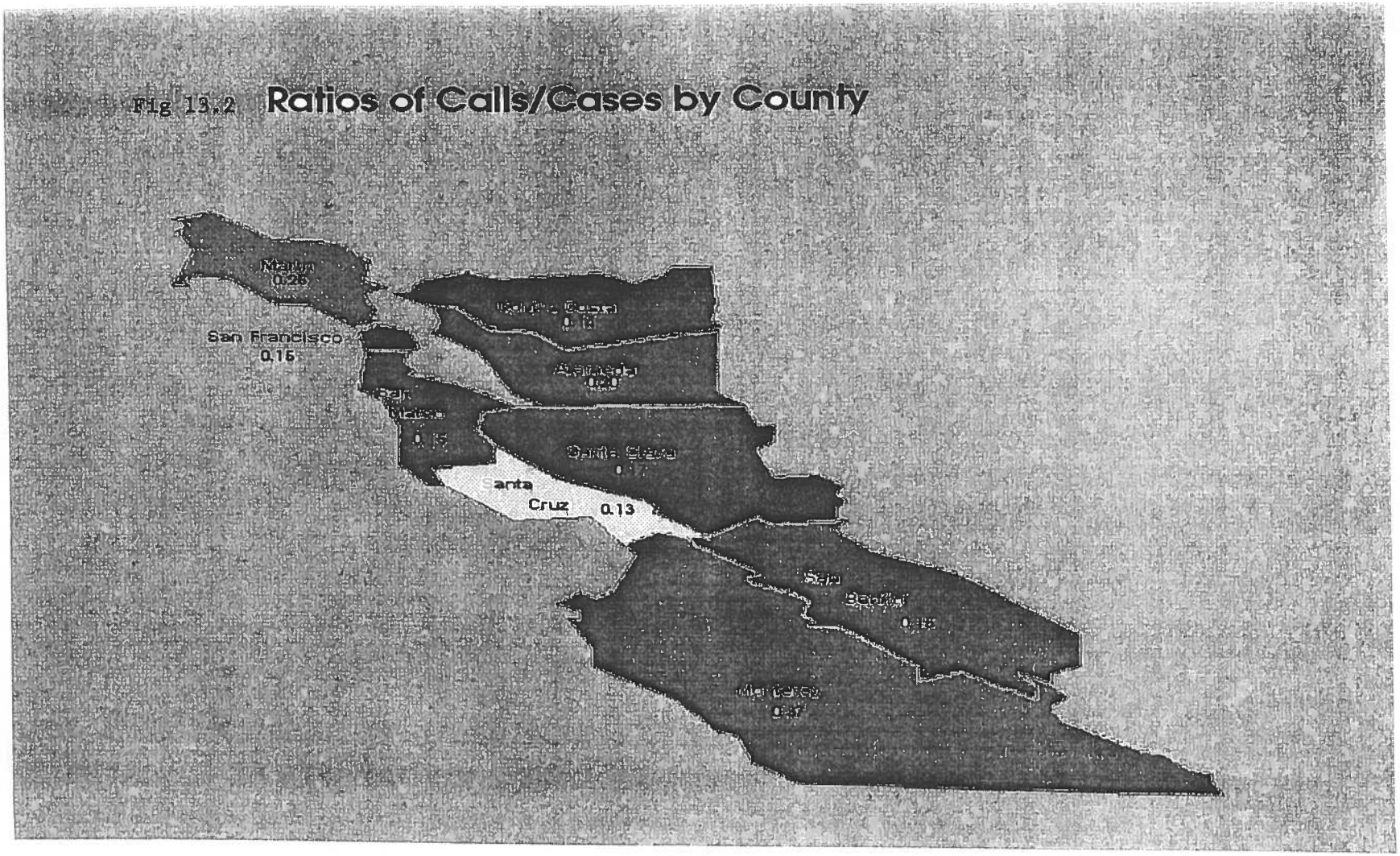


Fig 13.3 Plot of Calls by Cases: by counties

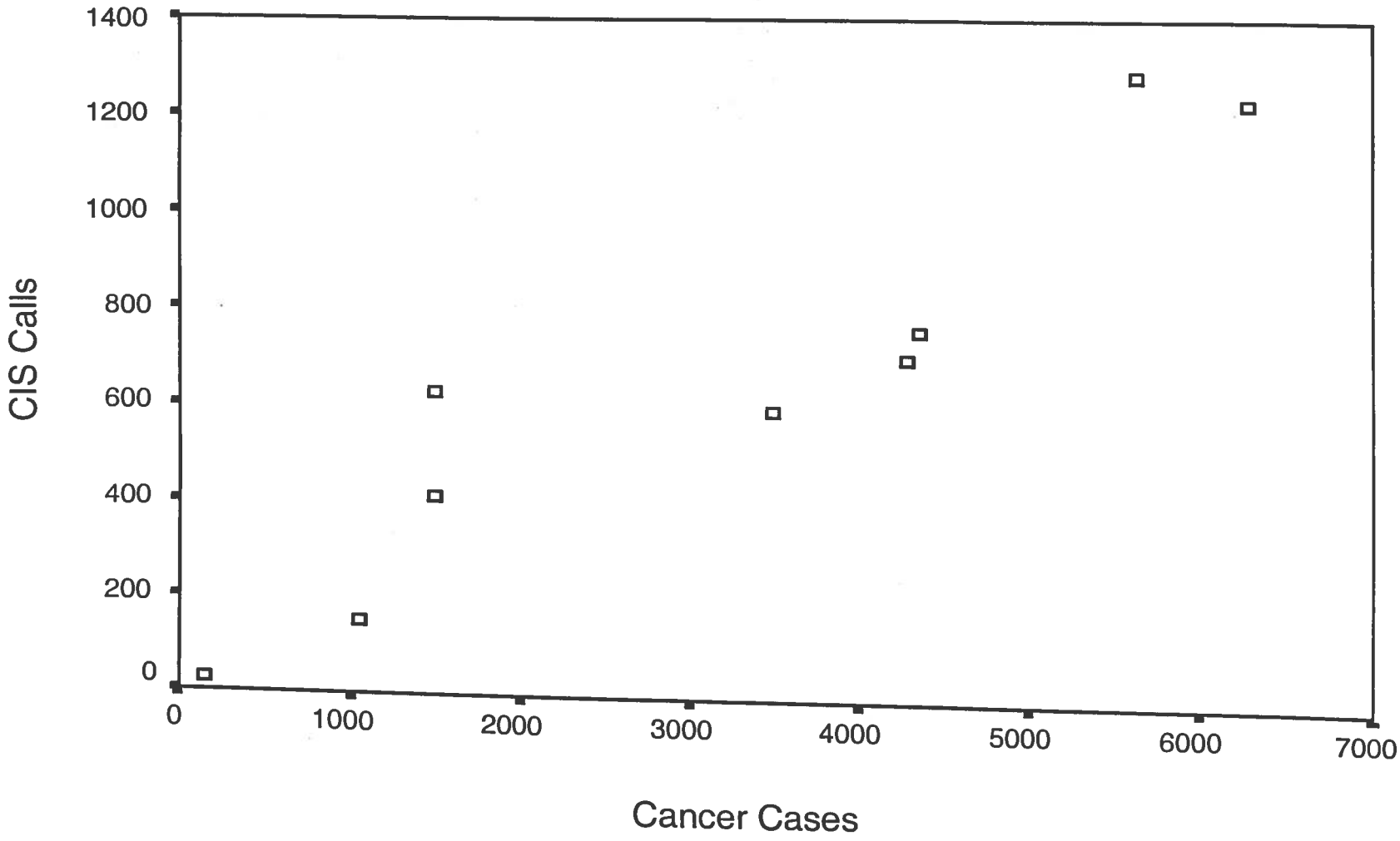


Fig 13.4: Plot of Calls/Cases Ratio by Popu Density

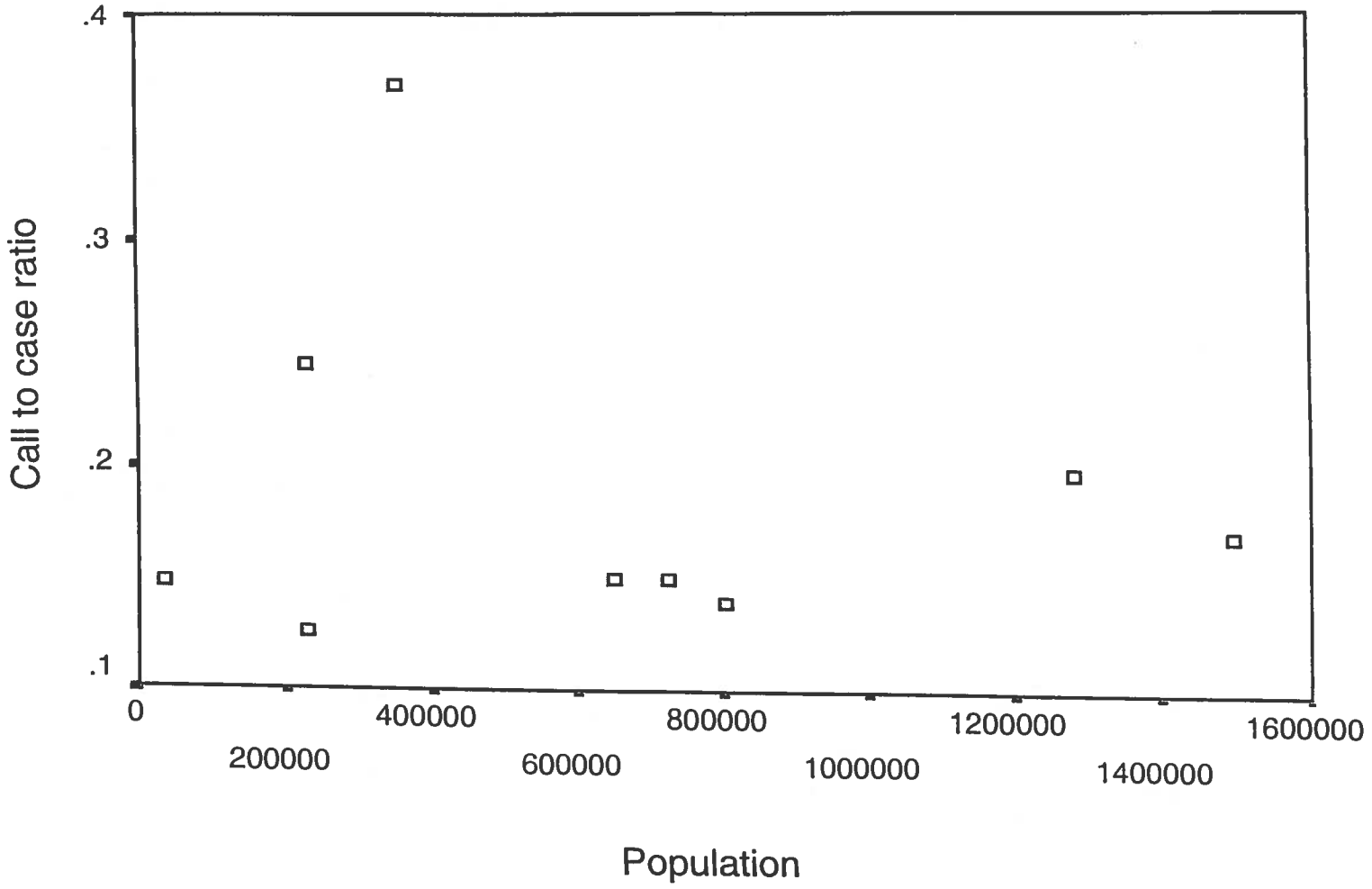


Fig 13.5: Ratios of County by Gender

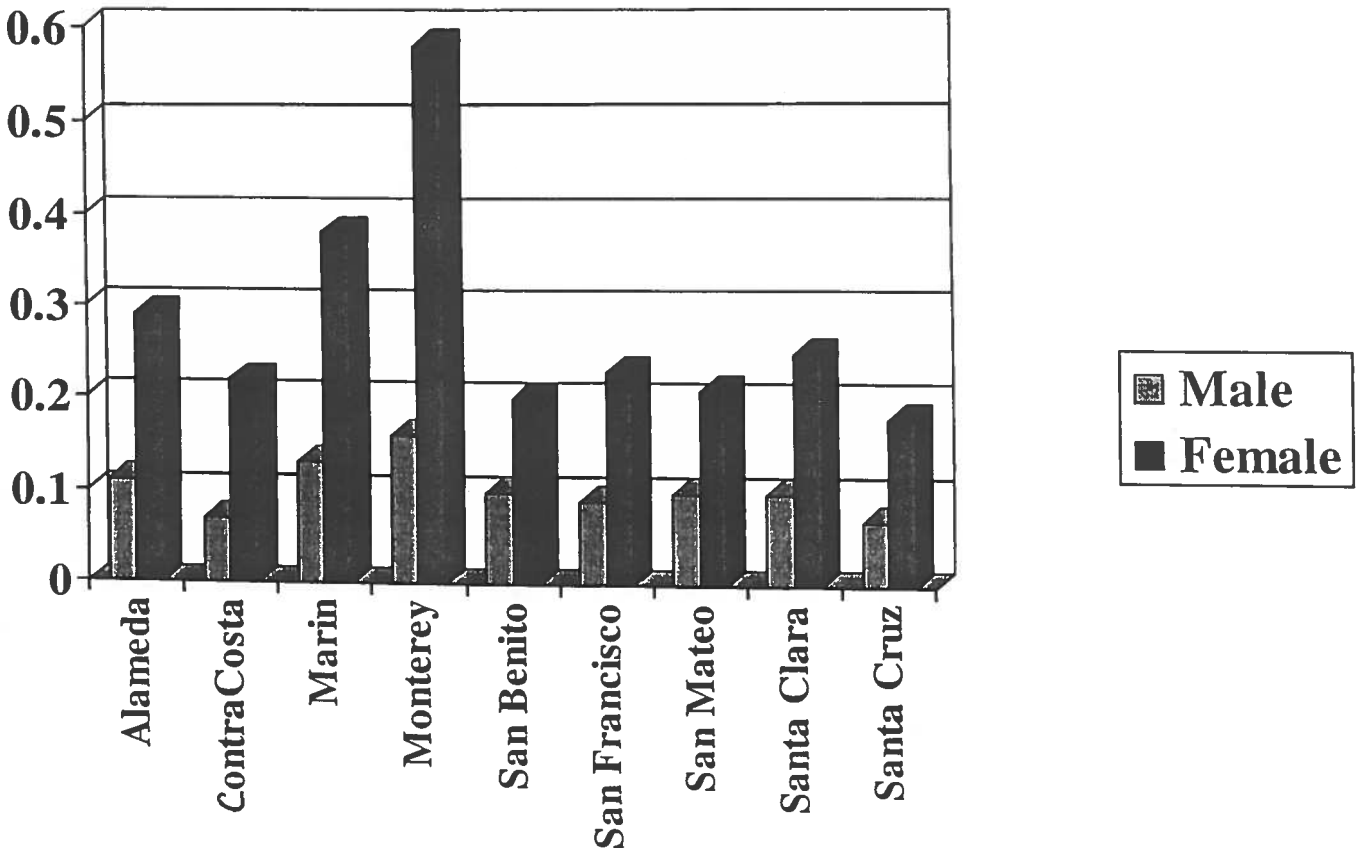


Fig 13.6: Ratios of County by Race/Ethnicity

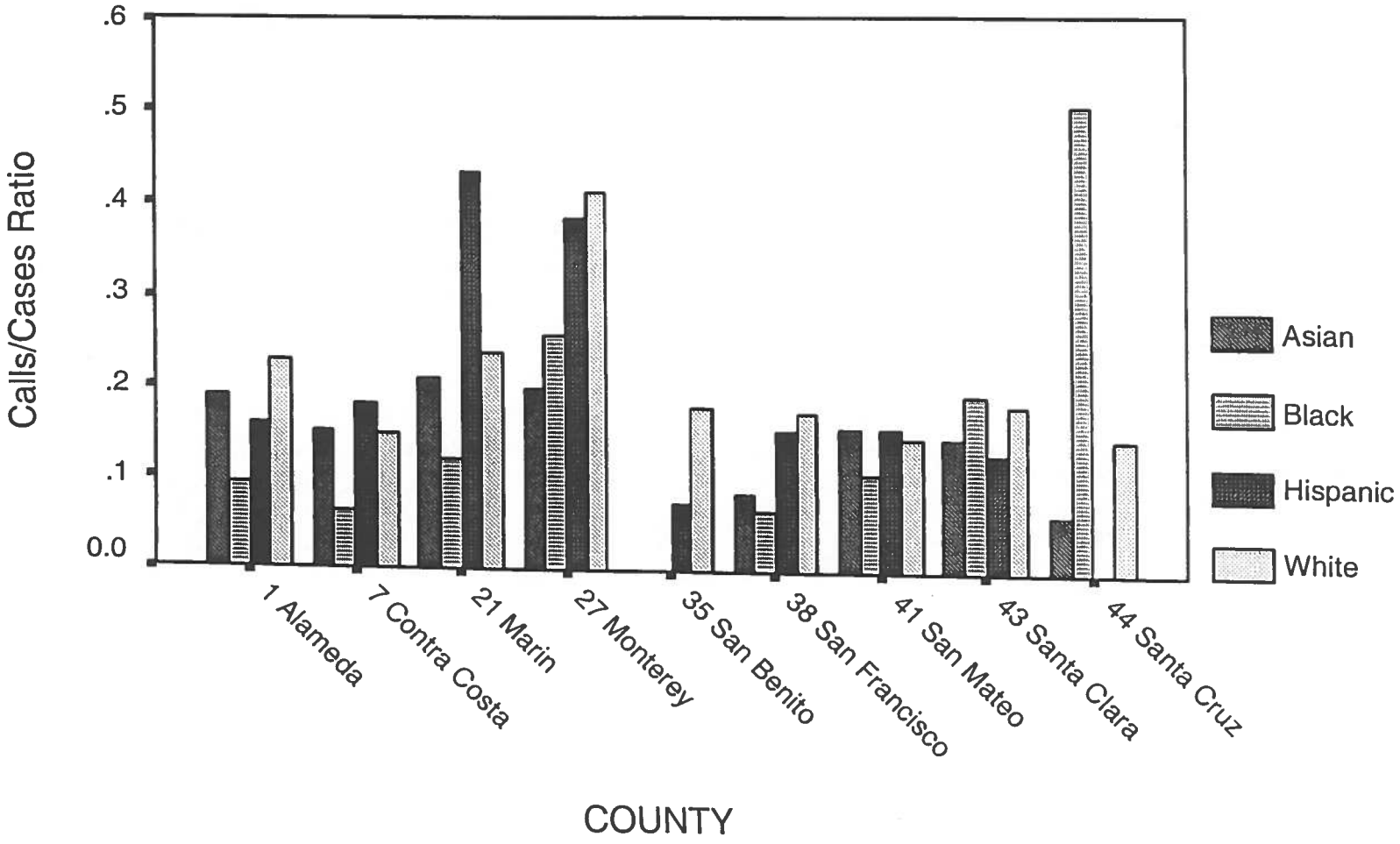
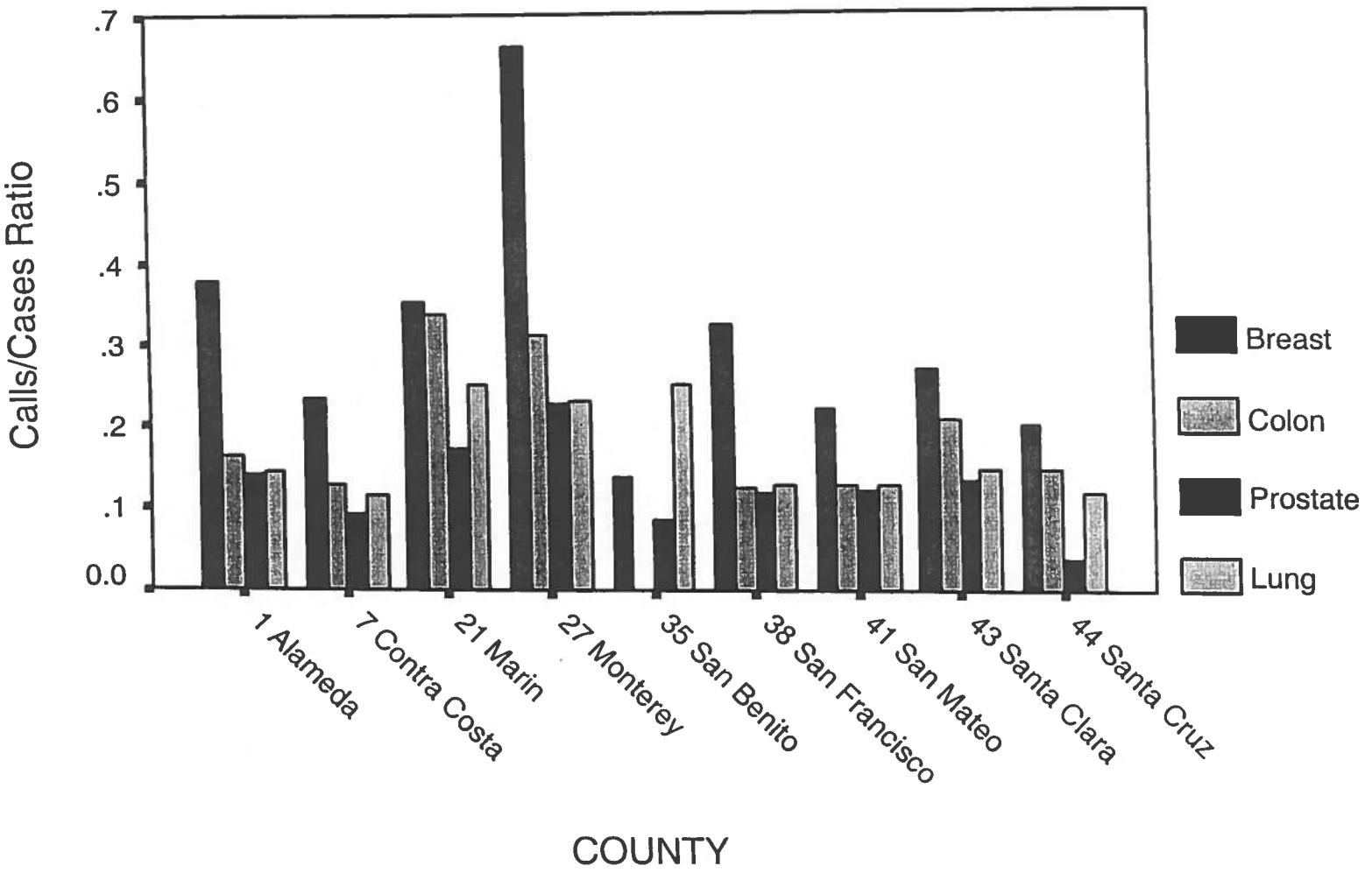
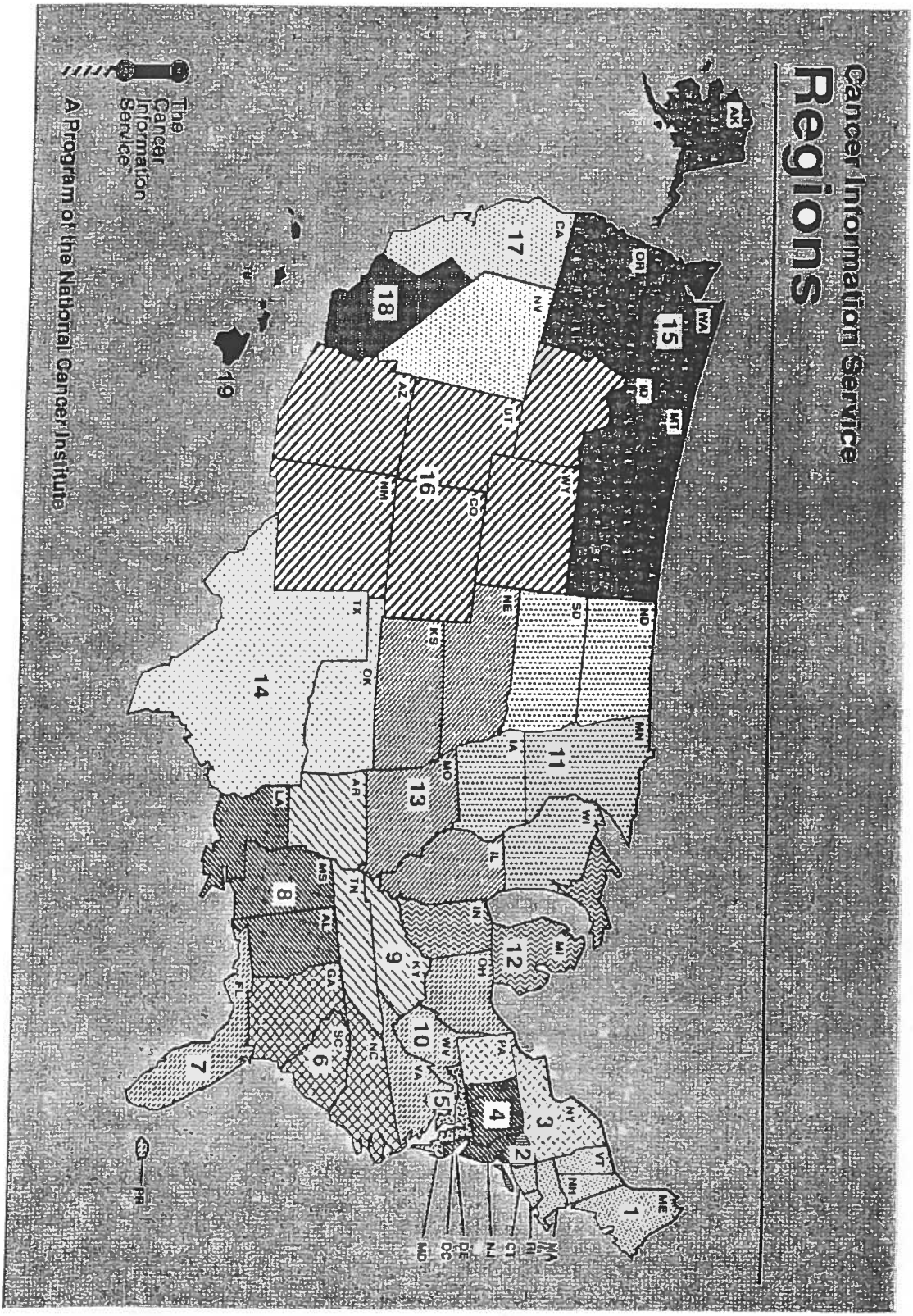


Fig 13.7: Ratios of County by Major Site




Cancer Information Service
Regions
AK
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OK
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The Cancer Information Service
A Program of the National Cancer Institute

CIS CALL RECORD FORM

Appendix 1b

rm approved: OMB No. 0937–0201,
expires 3/97

Time call begins [1][2][3][4] [5] 1 a.m. 2 p.m.

S region [6][7] Case [8][9][10][11][12][13][14] Staff I.D. [15][16] Date MONTH [17][18] DAY [19][20] YEAR [21][22]

ype of caller [23][24]

- Patient diagnosed by physician
- Spouse, relative, friend of diagnosed patient
- Undiagnosed person with symptoms
- Spouse, relative, friend of undiagnosed person
- General public
- 06 Student/parent of student
- 07 Organizational/Intermediary representative
- 08 Physician
- 09 Nurse
- 10 Media
- 90 Other health professional
- 95 Other nonhealth professional
- 99 Not able to ascertain

all Summary

aller Profile/Cancer Site:

bject:

sponse:

Subject of Inquiry [25][26][27] [28][29][30] [31][32][33] [34][35][36] [37][38][39]

Primary cancer site/type [40][41] [42][43] [44][45]

Response to Caller [46][47][48] [49][50][51] [52][53][54] [55][56][57] [58][59][60] [61][62][63] [64][65][66]

formation resources used on the phone [67][68][69][70] [71][72][73][74] [75][76][77][78]

- PDQ cancer treatment information for patients
- PDQ cancer treatment information for physicians
- PDQ protocols
- PDQ screening statements
- PDQ supportive care
- PDQ prevention statements
- NCI factsheet/publication
- 08 Subject matter file/NCI-approved textbook
- 09 CIS Resource Directory
- 10 CIS Staff
- 11 Public Inquiries
- 12 Subject matter specialist
- 13 Online databases (non-PDQ)
- 14 ACS factsheet/publication
- 15 Other non-NCI factsheet/publication
- 90 Other *Specify:* _____
- 99 None appropriate

edical disclaimer [79]

"I am a cancer information specialist, not a doctor, and can give you up-to-date information from the National Cancer Institute."

Medical disclaimer given: 1 Yes 2 No 9 Not applicable

1/2/97

We are always trying to improve our service. May I ask you a few questions to help us evaluate our program and see who we are serving? Your responses will be completely confidential.

Have you called the Cancer Information Service before?
1 Yes 2 No 3 Don't know 8 Refusal 9 Did not ask

What is your age? *(enter age)*
98 Refusal 99 Did not ask (84)

Are you female or male?
1 Female 2 Male 8 Refusal 9 Did not ask

What is your racial background? *(read categories and refer to local codes as appropriate)*
10 Asian/Pacific Islander 30 Hispanic 50 White 98 Refusal 99 Did not ask (87)
20 Black/African American 40 Native American/Alaska Native 60 Other/Mixed

What is the highest level of education you have completed? *(read categories)*
1 Grade school 3 High school graduate 5 College graduate 8 Refusal 9 Did not ask
2 Some high school 4 Some college 6 Post-graduate

What is your home ZIP code? (90) (91) (92) (93) (94) – (95) (96) (97)

How did you find our number to call today? *(use code sheet or codes below)*
998 Refusal 999 Did not ask (81) (82)

Is there anything else I can help you with?
Thank you for calling the Cancer Information Service. Please call us again if you have other questions.

Time call ends HOUR (106) (107) MINUTE (108) (109) a.m./p.m. (110) 1 2

Time for followup
1 None 4 11–15 minutes 7 26 minutes or more
2 1–5 minutes 5 16–20 minutes
3 6–10 minutes 6 21–25 minutes

Followup action (112) (113) (114) (115)
1 None 4 Send publications 7 Conducted PDQ search
2 Call back 5 Mail PDQ protocol/information 9 Other
3 Letter 6 NCI survey

Primary language used during call
1 English 2 Spanish 3 Other

Special codes (118) (119) (120) (121) (122)
1 Walk-ins 2 Mail/Fax

1/2

CIS ELECTRONIC CALL RECORD FORM CODING SHEET

1/2/97

SUBJECT OF INQUIRY:

Organizations
110 ACS
120 CDC
130 CIS
140 CIS parent institution
150 NCI
160 Non-cancer organization
170 Unconventional cancer organization
190 Other cancer-related organization

Health Professional
210 Consultation between professionals
220 Hospice
230 Hospital/clinic/screening program
240 Nursing home/extended care facility
250 Physician/second opinion
290 Other medical referral

Support Services
305 Counseling/support services
310 Diet/nutrition for cancer patients
315 Donation (money, time, equipment)
320 Equipment/supplies
325 Financial aid/insurance issues
330 Home care/visiting nurse
335 Legal issues/employment issues
340 Pain control
345 Physical and occupational rehabilitation
350 Transportation
390 Other support services

Prevention/Risk Factors
405 Alcohol
410 Asbestos
415 DES
420 Diet and nutrition for prevention
425 Drug/food additives
430 Environmental risks-nonoccupational
435 Environmental risks-occupational
440 Estrogen replacement therapy
445 Heredity
450 Natural/artificial UV exposure
455 Prevention trials
460 Radiation/X-ray
465 Sexual activity
470 Smokeless tobacco
475 Smoking
490 Other prevention/risk factors

Screening/Diagnosis
505 Screening BSE
510 Screening Pap
515 Screening FOBT
520 Screening mammogram
525 Screening PSA
530 Screening TSE
535 Screening trials
540 Other screening
550 Diagnostic-mammogram
555 Diagnostic-PSA
556 Diagnostic Trials
560 Other diagnostic test/diagnosis

Site Information
610 Site information, general
620 Metastasis
640 Patient care/follow-up
645 Supportive Care Trials
650 Prognosis
660 Recurrence
670 Statistics
680 Symptoms

Specific Treatment Information
705 Biological response modifiers
710 Bone marrow transplant
715 Chemotherapy
720 Clinical treatment trials
725 Cryotherapy
730 Gene therapy
735 Hormonal therapy
740 Laser therapy/photodynamic therapy
745 Radiation therapy
750 Side effects
755 Surgery
760 Treatment options, general
765 Unconventional methods
770 Treatment options, specific

Psychosocial Issues
810 Coping (including spirituality)
820 Grief and bereavement
830 Lifestyle changes (including job loss or change in activity)
840 Relationship with family
850 Relationship with physician
860 Sexuality/body image
890 Other psychosocial issues

Other
910 General cancer/other
915 Non-cancer call
920 Other research (basic)
925 Publications (bulk)
930 Publications (five or less)
935 CancerFax
936 CancerNet
940 Computer databases
945 PDQ
946 Outreach
951-974 National special codes
- 951 Prevention Trial - BCPT
- 952 Prevention Trial - PCPT
- 953 Screening Trial - PLCO
- 954 Breast Cancer Awareness Postal Stamp
- 955 Cost Recovery (Bulk Orders)

956 NCI Fallout study 8/11/97
956-974 Unassigned
975-997 Local special codes
999 Not able to ascertain

PRIMARY CANCER SITE/TYPE:

AIDS-Related Cancers
01 AIDS-related lymphoma
02 AIDS-related Kaposi's sarcoma
03 Other AIDS-related cancers

Breast Cancer
05 Breast cancer

Digestive/Gastrointestinal System
06 Esophageal cancer
07 Gastric cancer
08 Colon cancer
09 Rectal cancer
10 Gallbladder cancer
11 Pancreatic cancer
12 Primary liver cancer
13 Other or unspecified or digestive system, general

Endocrine/Thyroid
15 Thyroid cancer
16 Other or unspecified or endocrine/thyroid, general
22 Other or unspecified or head and neck, general

Lymphatic and Circulatory System
25 Leukemia
26 Hodgkin's disease
27 Non-Hodgkin's lymphoma
28 Plasma cell neoplasm
29 Other or unspecified or lymphatic or circulatory system, general

Kidney/Urinary System
30 Bladder cancer
31 Renal cell cancer
32 Wilms' tumor
33 Other or unspecified or urinary system, general

Musculoskeletal, Connective, and Soft Tissue
35 Soft tissue sarcoma
36 Rhabdomyosarcoma
37 Ewing's sarcoma
38 Osteosarcoma
nervous system, general

Female Genital/Reproductive System
45 Cervical cancer
46 Uterine cancer
47 Ovarian cancer
48 Other or unspecified or female reproductive, general

Male Genital/Reproductive System
50 Prostate cancer
51 Testicular cancer
52 Other or unspecified or male reproductive, general

Skin
55 Nonmelanoma skin cancer
56 Melanoma
57 Other or unspecified or skin cancer, general

Respiratory System/Thorax
60 Lung cancer
61 Malignant mesothelioma
62 Other or unspecified or respiratory,

Support Services
305 Counseling/support services
310 Diet/nutrition for cancer patients
315 Donation (money, time, equipment)
320 Equipment/supplies
325 Financial aid/insurance issues
330 Home care/visiting nurse
335 Legal issues/employment issues
340 Pain control
345 Physical and occupational rehabilitation
350 Transportation
390 Other support services

Prevention/Risk Factors
405 Alcohol
410 Asbestos
415 DES
420 Diet and nutrition for prevention
425 Drug/food additives

530 Screening TSE
535 Screening trials
540 Other screening
550 Diagnostic-mammogram
555 Diagnostic-PSA
556 Diagnostic Trials
560 Other diagnostic test/diagnosis

Site Information
610 Site information, general
620 Metastasis
640 Patient care/follow-up
645 Supportive Care Trials
650 Prognosis
660 Recurrence
670 Statistics
680 Symptoms

Specific Treatment Information
705 Biological response modifiers
710 Bone marrow transplant
715 Chemotherapy
720 Clinical treatment trials

880 Sexuality/body image
890 Other psychosocial issues

Other
910 General cancer/other
915 Non-cancer call
920 Other research (basic)
925 Publications (bulk)
930 Publications (five or less)
935 CancerFax
936 CancerNet
940 Computer databases
945 PDQ
946 Outreach
951-974 National special codes
- 951 Prevention Trial - BCPT
- 952 Prevention Trial - PCPT
- 953 Screening Trial - PLCO
- 954 Breast Cancer Awareness Postal Stamp
- 955 Cost Recovery (Bulk Orders)
- 956-974 Unassigned

956 NCI fallout study 8/1/97

975-997 Local special codes
999 Not able to ascertain

<u>PRIMARY CANCER SITE/TYPE:</u>

AIDS-Related Cancers
01 AIDS-related lymphoma
02 AIDS-related Kaposi's sarcoma
03 Other AIDS-related cancers

Breast Cancer
05 Breast cancer

Digestive/Gastrointestinal System
06 Esophageal cancer
07 Gastric cancer
08 Colon cancer
09 Rectal cancer
10 Gallbladder cancer
11 Pancreatic cancer
12 Primary liver cancer
13 Other or unspecified or digestive system, general

Endocrine/Thyroid
15 Thyroid cancer
16 Other or unspecified or endocrine/thyroid, general

Eye
17 Intraocular melanoma
18 Retinoblastoma
19 Other or unspecified or eye, general.

Head and Neck
20 Lip and oral cavity cancer
21 Laryngeal cancer
22 Other or unspecified or head and neck, general

Lymphatic and Circulatory System
25 Leukemia
26 Hodgkin's disease
27 Non-Hodgkin's lymphoma
28 Plasma cell neoplasm
29 Other or unspecified or lymphatic or circulatory system, general

Kidney/Urinary System
30 Bladder cancer
31 Renal cell cancer
32 Wilms' tumor
33 Other or unspecified or urinary system, general

Musculoskeletal, Connective, and Soft Tissue
35 Soft tissue sarcoma
36 Rhabdomyosarcoma
37 Ewing's sarcoma
38 Osteosarcoma
39 Other or unspecified or musculoskeletal, connective, and soft tissue, general

Central Nervous System
40 Brain
41 Neuroblastoma
42 Other or unspecified or central nervous system, general

Female Genital/Reproductive System
45 Cervical cancer
46 Uterine cancer
47 Ovarian cancer
48 Other or unspecified or female reproductive, general

Male Genital/Reproductive System
50 Prostate cancer
51 Testicular cancer
52 Other or unspecified or male reproductive, general

Skin
55 Nonmelanoma skin cancer
56 Melanoma
57 Other or unspecified or skin cancer, general

Respiratory System/Thorax
60 Lung cancer
61 Malignant mesothelioma
62 Other or unspecified or respiratory, general

Other
90 Carcinoma of unknown primary
91 Myeloproliferative disorders
92 Other
99 Not applicable/no specific site mentioned

<u>YOUR RESPONSE TO CALLER:</u>

<u>Introduced Behavioral Suggestions</u>

Health Professional
110 Get a second opinion
120 Introduce clinical trials
130 Seek screening
140 Talk to or visit other health professional
150 Talk to, visit, or share with physician

Personal
210 Introduce smoking cessation
220 Modify diet
230 Practice occupational safety
240 Practice other prevention/self-detection/risk reduction

Share Information
260 Share information with another
270 Tell others to call CIS

Other Behavioral Suggestions
300-345 National special codes
346-389 Local special codes
390 Other behavioral suggestions

continued on next page

YOUR RESPONSE TO CALLER

(continued from previous page)

Provided Information Only

399 Did not provide behavioral suggestions, support, or referral

Gave Support

400 Clinical trials
405 Coping
410 Diet and nutrition
415 Pain
420 Physician relations
425 Smoking/tobacco use
430 Survivorship
435-460 National special codes
461-489 Local special codes
490 Other support

Provided Referral

NCI-Affiliated Referral

500 ALIC
505 ASSIST
510 CIS-other regional office
515 CIS-outreach coordinator (in region)
520 CIS parent institution
525 NBLIC
530 NCI-designated cancer center
535 NCI Treatment Centers
540 NHLIC
545 PDQ clinical trial
550 POS
555 Other NCI programs

Health Professional Referral

600 Professional counseling/support
605 Home care
610 Hospice
620 Hospital/clinic
630 Medical society
640 Non-PDQ trial
650 Nursing home/extended care facility
660 Screening facility

Community Referral

700 ACS
710 CDC
720 Community service
730 Library

Other Referral

801 PDQ referral
802 Other computer referral
803 IAP referral
804 PDQ search service for professionals
805 Other referral
810-850 National special codes
- 810 Prevention Trial-BCPT
- 811 Prevention Trial-PCPT
- 812 Screening Trial-PLCO
- 813-850 Unassigned

851-899 Local special codes
999 None appropriate

HOW FOUND OUT

100 Relative/friend
101-149 National special codes
150-199 Local special codes
200 Health professional
201-249 National special codes
250-299 Local special codes
300 TV
301-349 National special codes
- 301 Good Morning America
- 302 ABC Nightly News
- 303 Today Show
- 304 NBC Nightly News
- 305 CBS This Morning
- 306 CBS Evening News
- 307 Home Show
- 308 Telemundo
- 309 Black Entertainment TV
- 310 General Hospital
- 311 Postal Service PSAs
- 312 NHLIC PSAs
- 313 NBC Dateline
- 314 Univision
- 315 Angela Bassett TV PSA
- 316 Ricki Lake Show
- 317 Primetime Live
- 318-349 Unassigned

350-399 Local special codes
400 Radio
401-449 National special codes
- 415 Angela Bassett RADIO PSA

450-499 Local special codes500 Magazine
501-549 National special codes
- 501 Modern Maturity/AARP Newsletter
- 502 Reader's Digest
- 503 Parade Magazine
- 504-549 Unassigned

550-599 Local special codes
600 Newspaper
601-649 National special codes
- 601 New York Times
- 602 Washington Post
- 603 National Enquirer
- 604 USA Today
- 605 Ann Landers/Dear Abby Column
- 606-649 Unassigned

650-699 Local special codes
700 NCI publications
701-749 National special codes
750-799 Local special codes
800 Organization/community group
801-849 National special codes
- 801 ACS
- 802 ALIC
- 803 ASSIST
- 804 CIS parent institution
- 805 CDC
- 806 NBLIC
- 807 NCI-designated cancer center
- 808 NHLIC
- 809 Other 800 service
- 810 POS
- 811 State health department
- 812 Richard Bloch
- 813 BCPT
- 814 PCPT
- 815 PLCO
- 816 BrCa1
- 817 Breast Cancer Awareness Postal Stamp
- 818 Mill Pond Press/Art Nature Magazines
- 819 AARP/ACS/NCI Exhibit
- 820 National Coalition for Cancer Survivorship (NCCS)
- 821-849 Unassigned

850-899 Local special codes
900 Phone book/directory assistance
901 Other printed source
902 Other
903 "I just know it"
904 Internet
905-997 Unassigned
998 Refusal
999 Did not ask

SPECIAL CODES

1-5 National Special Codes
- 1 Walk-ins
- 2 Mail/Fax
- 3-5 Unassigned

6-9 Regional Special Codes
10-49 National Special Codes
50-99 Regional Special Codes

Appendix 2: Collapsed Categories of different variables of the CIS ECRF

Caller type:
patient diagnosed by physician
spouse, relative, friend of diagnosed patient
undiagnosed patient with symptoms
spouse, relative, friend of undiagnosed person, general public
other professionals

Subject of inquiry:
organizations
health professional
support services
prevention/risk factors
screening/diagnosis, site information
specific treatment information
psychosocial issues
other

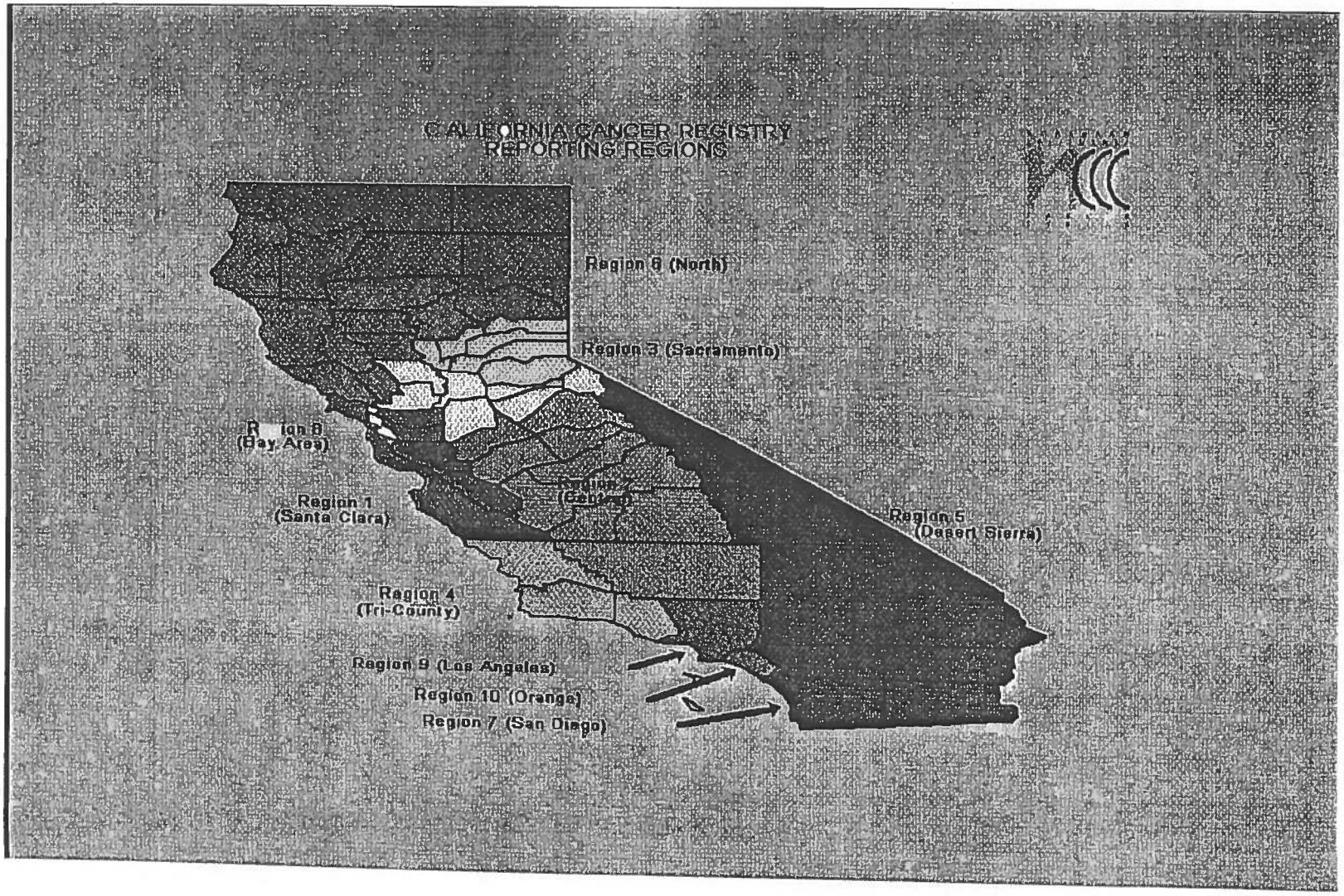
Primary cancer sites:
AIDS related cancers
breast cancer
cancer of the digestive/gastrointestinal system
endocrine/thyroid
eye
head and neck
lymphatic and circulatory systems
kidney/urinary system
musculoskeletal, connective, and soft tissue
central nervous system
female genital and reproductive system
male genital/reproductive system
skin
respiratory system/thorax
other
not applicable

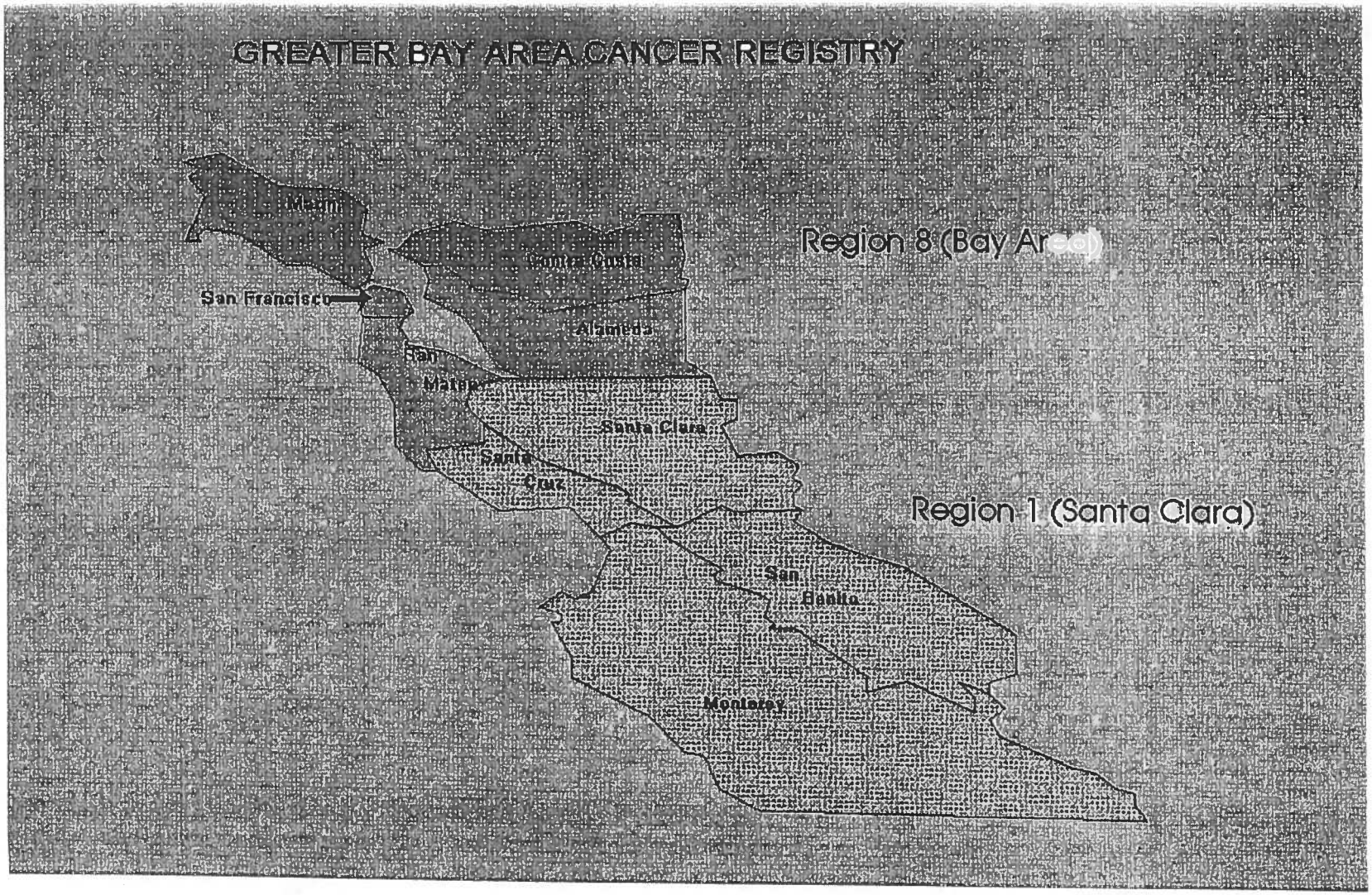
Responses to callers:
introduced behavioral suggestions
provided information only
gave support
provided referrals

Information resources used by the specialists:
PDQ
NCI fact sheet or publications
secondary resources
none appropriate

How the callers found out about CIS:
relatives or friends
health professional
media
NCI publications
organization
phone book
other

Follow up actions:
none
send publications
mail PDQ protocol/information
others


CALIFORNIA CANCER REGISTRY
REPORTING REGIONS
Region 6 (North)
Region 3 (Sacramento)
Region 8
(Bay Area)
Region 1
(Santa Clara)
Region 5
(Desert Sierra)
Region 4
(Tri-County)
Region 9 (Los Angeles)
Region 10 (Orange)
Region 7 (San Diego)


GREATER BAY AREA CANCER REGISTRY
Marin
Contra Costa
San Francisco
Alameda
San
Mateo
Santa Clara
Santa
Cruz
San
Benito
Monterey
Region 8 (Bay Area)
Region 1 (Santa Clara)

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e-mail: subjects@uclink4.berkeley.edu
Web Site: http://socrates.berkeley.edu:7006

March 3, 2000

Hui Zhang
515 Oak Street, #2
El Cerrito, CA 94530

RE: "A Comparison of Cancer Information Service (CIS) Call Volume in Region 17 to Cancer Incidences in the GBACR" Dissertation Researhc - School of Public Health/Health and medical Sicences

Dear Mr. Zhang:

Thank you for the statement and request for exemption that you submitted to the Committee for the project referred to above. As described in the statement, your research satisfies the Committee's requirements under Exemption #6, page 5, of CPHS Guidelines of January 1998 (Exemption #4 of the Federal Regulations.) Accordingly, the project is exempt from full Committee review provided that there are no changes in the use of human subjects.

For our records, the number of the project is 2000-3-78. Please refer to this number in any future correspondence about the project.

If you have any questions about this matter, please contact the CPHS staff at 642-7461; FAX 643-6272; Email subjects@uclink.berkeley.edu.

Sincerely,

Judith Warren Little
Professor of Education
Chair, CPHS

JWL:nan
cc: Professor Patricia Buffler
Graduate Assistant
Graduate Division (SID #11075789)