1990

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Recommended Citation

Nutting PA. Helgerson SD. Beaver SK. Bates PM. Berg LE. Copp D. Tyson H. Preventable cancer mortality in American Indian and Alaska Native women. Indian Health Service, Staff Office of Planning, Evaluation and Research, Rockville, MD 20857. 1990

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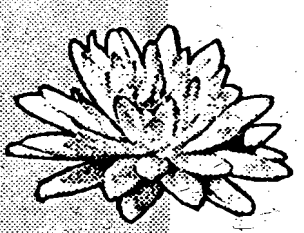

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Public Health Service
Indian Health Service
Indian Health Service . . Office of Health Program Research & Development

7900 South J. Stock Road . . Tucson . . Arizona . . 85746-9352

PREVENTABLE CANCER MORTALITY IN AMERICAN INDIAN AND ALASKA NATIVE WOMEN

1 May 1990

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This work was supported with funding from the
Office of Planning Evaluation and Legislation, IHS
Ramona Ornelas, Project Officer
and
National Cancer Institute, NIH
(Contract No. Y02-CN-90667)
Gregory Christianson, Ph.D., Project Officer

Indian Health Service Research Program
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I. SUMMARY AND CONCLUSIONS

Shifts in the patterns of illness among American Indian and Alaska Native (AI/AN) commuities underscore the need to better understand patterns and correlates of chronic disease. The development of new knowledge that describes patterns of occurence and patterns of care for chronic disease is critical to support the development and implementation of intervention strategies to deal more effectively with a growing burden of illness due to chronic conditions. Although cancer rates are generally believed to be relatively lower in AI/AN populations, the available statistics suggest a relatively poor survival experience for cancer patients. This report describes a series of six studies on cancer in American Indian and Alaska Native women, with a particular emphasis on cancer of the breast and cervix. The work was supported with funds from the Office of Planning, Evaluation, and Legislation of the Indian Health Service and from the National Cancer Institute under contract Y02-CN-90667.

The six studies reported here bring to bear a substantial body of information with relevance to IHS clinical policy. Although each study discusses its results in detail, several findings deserve emphasis and others are most apparent when considered across several studies.

A. Burden of Cancer Illness

Perhaps the most important finding is that confirming the substantial variation in cancer rates among IHS administrative areas and among tribal groups. Breast cancer rates show substantial variation among Areas and Tribes, but are consistently below that observed by the general U.S. female population. Unlike the general population, however, for the AI/AN women the rates of cervical cancer equal and may exceed the rates of breast cancer in some IHS areas. Hopefully, these data will reduce the frequency of inappropriately general statements about the frequency of cancer in AI/AN communities, and instead focus attention on the need for better explanations of the observed variation and, most importantly, of the need for clinical policy that is consistent with the rates observed in the local community.

There is less difference between AI/AN women and the general population for cancer mortality rates. For all site incidence only the Alaska Area exceeded the general population, yet for all site mortality the Billings and Aberdeen Areas also exceed the rates for the general population. The relationship between incidence (new cases) and mortality should be interpreted cautiously, and several factors may contribute to the relationship. First, the data were derived from different sources and could result in relative under or overcounting of the cases, the deaths, or the populations at risk. Second, the distribution of cancers by site may vary, with the Area burdened by more lethal cancers showing a mortality rate out of proportion to the incidence. Third, the mortality data are derived from death certificate data and do not distinguish among individuals eligible and ineligible for IHS care. Consequently, the analysis used only those states in which more than 80% of AI/ANs were believed eligible for care by the IHS. This procedure resulted in sampling by state for some Areas, e.g., the mortality for the Billings Area represents only cancer deaths in Montana. Finally, discrepancies in the incidence to mortality relationship could result from variation in the adequacy of care by IHS Area, principally variation in early detection and treatment. Although this is a finding that deserves a great deal more attention (subsequent studies are currently underway), attributing the observed variation to health care factors would be premature.

B. Methods Issues

Data from the IHS inpatient data system appear to be useful in generating estimates of incidence of cancer among AI/AN populations. Breast cancer rates among Indian women in Arizona and New Mexico derived from extensive chart review confirmation of data from the New Mexico Tumor Registry compare favorably with those derived from the IHS Inpatient Data System. This is encouraging in light of the substantial commitment of research resources to using existing data sets to improve our understanding of the morbidity and mortality rates among AI/AN communities that are attributable to chronic disease.

The documentation of screening in the medical record continues to be a problem for studies of cancer screening. The study of breast cancer reported in Section VII found that only 43% of women had a clinical breast examinations performed during the previous five years. On the other hand, the study that reviewed medical records that included the PCC encounter form observed 64% with a clinical examination during the previous three years. It is unlikely that there is this much difference in the practice patterns of the primary providers and much of the difference is attributed to variation in provider documentation. The PCC encounter form has a check box for breast exam that is believed to encourage documentation of tasks done. This is a discouraging finding for investigators hoping to obtain accurate data on breast examinations from the standard medical record.

The study on rates of cancer in women reported in Section III reports 95% confidence intervals for the rate estimates. For many IHS areas the confidence intervals are wide, but are even wider for rates reported for specific tribes. These rates are based on six years of inpatient data and it is interesting to note that the rates reported in the breast cancer study (Section VII) report narrower confidence intervals for two of the same tribes based on nine years of observation. Future studies that attempt to estimate incidence rates for specific tribes would be advised to use an 8 to 10 year time frame, if possible.

C. Patterns of Care

Study of the performance of the health care system for cancer screening in women suggested that the major deficiency lies not in a failure to bring women in for screening, but rather to complete the screening after contact had been made and the need for screening recognized. The low completion rates for referral and appointments to a special women's clinic raise serious question about the value of such an arrangement. While the appropriateness of completing cancer screening by female providers is not argued, the data from this site suggest that requiring a separate visit for women's clinic may provide an opportunity for procrastination for those women less than fully enthusiastic to participate in a Pap smear and breast examination. Further study of the impact of separate women's clinics is underway.

IHS policy has been greatly influenced by a recent study from the New Mexico Tumor Registry reporting that cancer is generally diagnosed in American Indian women at a more advanced stage and survival experience of Indian cancer patients is worse than non-Indian, even when corrected for later stage at diagnosis. The data used in the decision model of Section VIII confirm both of the these findings for breast cancer in Indian women in Arizona and New Mexico, but suggest that a disproportionate share of the adverse cancer experience occurs in the numerically large Navajo

Nation. Figure 1 shows the distribution of stage at diagnosis for Navajo women compared to all non-Navajo Indian women in Arizona and New Mexico. Figure 2 compares the probability of five-year survival by stage at diagnosis for Navajo women, non-Navajo Indian women, and all women reported by the SEER program. In both cases the experience of Navajo women appear to be substantially worse than that of other Indian women in the Southwest. A separate study is underway to examine further this disparity, and the implications for clinical policy in the Albuquerque, Phoenix, Navajo and Tucson Areas of IHS. Similarly, the study reported in Section VII provides evidence that the distribution of breast cancer stage at diagnosis of non-Navajo Indians in Arizona and New Mexico is comparable to that observed in hispanic patients in New Mexico. Thus, it is suggested that much of the adverse cancer experience among American Indians reported from the New Mexico Tumor Registry is due to the experience of the Navajo. Two studies are currently underway to followup on this suggestion.

D. Implications for Clinical Policy

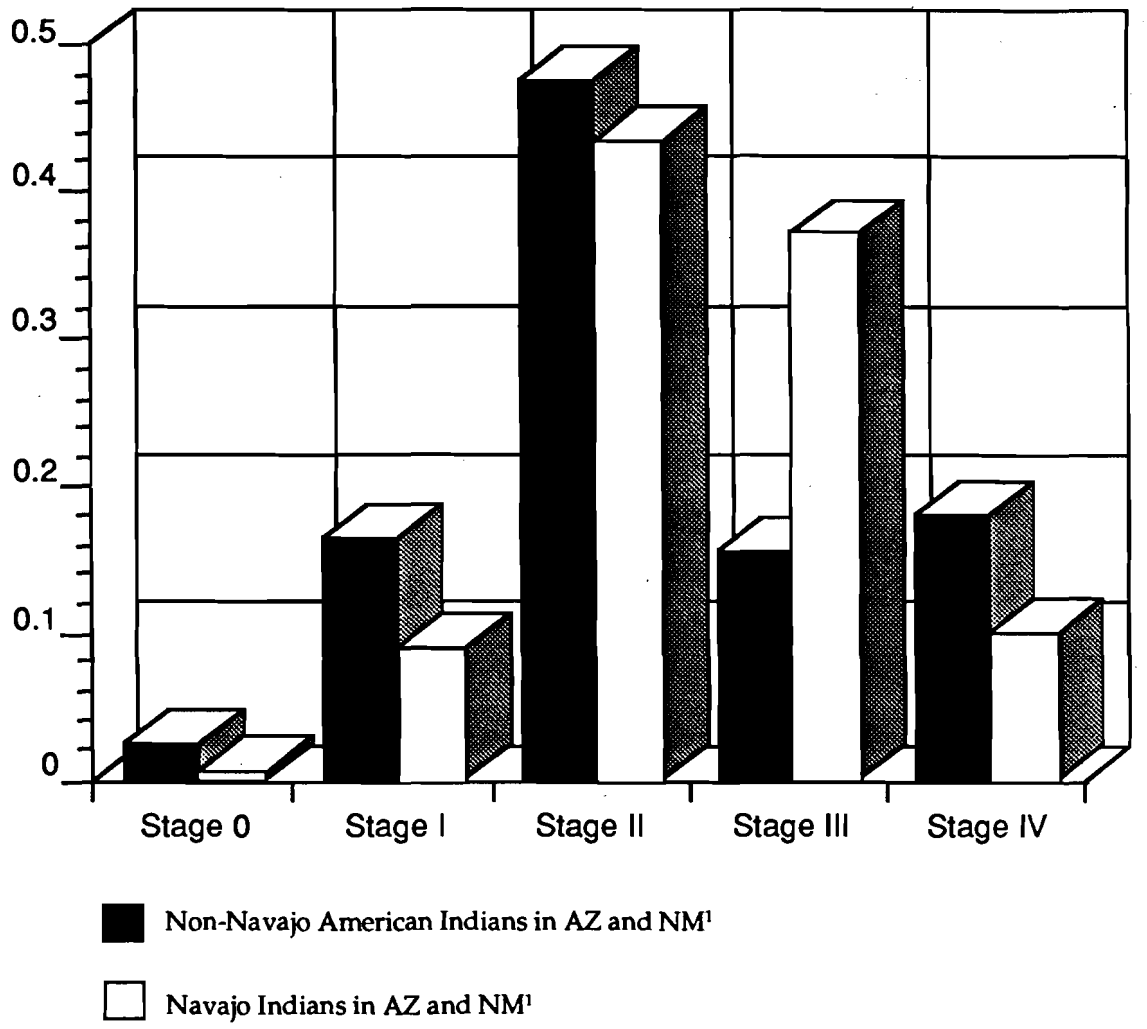
The analysis of policy options for breast cancer screening reported in Section VII suggests that for a given population the cost of screening is 15% higher for mammography compared to a strategy of clinical breast examination, but results in a 20% reduction in breast cancer deaths over the first five years of the program. This compares to an 8.1% reduction in deaths with a strategy that relies on clinical breast examination as the screening test.

Since the rates of breast cancer are relatively low in most IHS areas an analysis was made of the effect of varying incidence on the cost and effectiveness ratio of breast cancer screening strategies. Interestingly, this analysis suggests that both costs and deaths prevented are sensitive to changes in baseline incidence in the population and that the cost-effectiveness relationships are less favorable in the range of incidence common in most AI/AN communities.

The analysis also examined the relative impact of improving stage at diagnosis (through improved screening) compared to the impact of improving stage-specific survival (through case management strategies). When applied to the age-sex structure of the Navajo Nation, the results suggest that reductions in mortality comparable to those achieved by improved screening, could also be achieved through case management strategies that improved the stage specific survival. Even greater reductions (nearly 60%) in mortality could be achieved through combinations of both screening and case managment. Important and equally dramatic effects are also seen for other Indian populations in the southwest. This finding emphasizes the pitfall of developing a preoccupation with a single strategy for improving health status, when multiple strategies may be needed to achieve substantial gains.

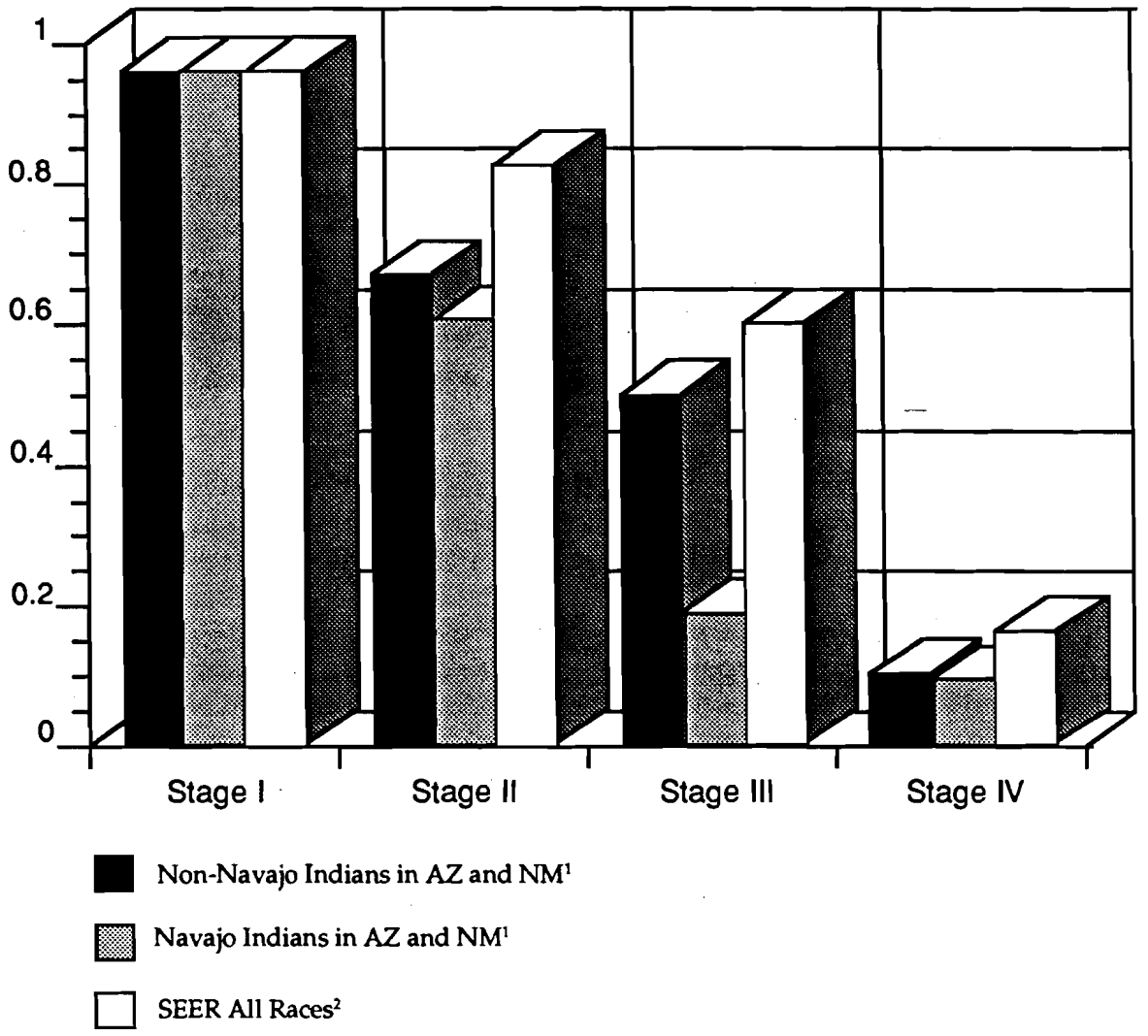
Several of the studies suggest that failure to diagnose cancer in its very early stages appears to be in large part dependent on patient behavior. In study of screening for cervical cancer (Section IV), the major drop-out point in the process of care appears to be after a visit has been made and the need for a Pap smear has been recognized. Often this is planned during a separate visit, although an alarming number of women do not keep their appointments, even after multiple referrals and rescheduling of appointments. In the study of breast cancer screening reported in Section VII, a substantial number of women were found to have discovered a breast lump, but delayed examination by a physician for up to 18 months. This was particularly apparent in post-menopausal women and in women with late stage tumors at diagnosis. These findings suggest

Figure 1: Distribution of Stage at Diagnosis. Stage is expressed according to TNM criteria at the American Joint Commitee on Cancer.



[1]From the New Mexico Tumor Registry (1973-1988) and includes American Indians in Arizona and New Mexico.

Figure 2: Survival at Five Years for Breast Cancer by Stage of Diagnosis.



[1]Data are from the New Mexico Tumor Registry and include cancer cases in American Indians in Arizona and New Mexico diagnosed between 1973-88. Individual cases are included in the analysis only if status were known to the NMTR at five years, i.e., individuals lost to followup are not included.
[2]Reported by Levin et al, ref. 13

the need for intervention strategies that encourage women to become knowledgeable about cancer and to accept responsibility for their screening. Finally, in questioning IHS providers about their perceptions of how improvements in cancer control might be accomplished (reported in Section VI), there was a strong suggestion that the relative difficulty in improving screening rates could be traced to an inadequate understanding of cancer and its prevention on the part of women in the community.

A substantial body of work is underway to develop an instrument to measure patient knowledge, attitudes, and self-reported behaviors (KABs) regarding breast and cervical cancer. Since this work is still in progress, the brief report in Section V simply reports the status of the developmental effort. The eventual ability to assess KAB factors related to observed behaviors (e.g. failure to return for a visit scheduled to complete an annual Pap smear, failure to participate in a screening mammography program, etc.) will provide addition and critical information for program designers, program managers, and those involved in creating and modifying clinical policy for the IHS and tribal health programs.

The study of breast cancer reported in Section VII describes a worrisome level of confusion over priorities for mammography at the local level. First, there appears to be confusion over the use of mammography as a screening test (applied to women with no signs or symptoms of disease) versus its use as a diagnostic test (applied to a woman with a documented breast mass). Cases were discovered in which a woman with a documented breast mass was put in the CHS queue, with a resulting delay that may have permitted advancement of the breast cancer. Clearly, mammography for a known lesion is a diagnostic rather than a screening procedure, and local policies that confuse the two separate functions of mammography are ill-conceived and inappropriate. Second, priorities can be established for screening as a function of known risk factors. For some risk factors, such as a history of breast cancer in a first degree relative, screening mammography should be a high priority for CHS funds. At the very least each program can specify those risk factors that deserve screening mammography, judged in part by the estimated incidence of breast cancer in that population.

II. INTRODUCTION

A. Background

The Indian Health Service continues to face enormous challenges in assuring adequate primary health care services to the American Indian and Alaska Native (AI/AN) communities. Since 1955, however, the profile of priority health problems has shown a continuing shift from infectious disease to chronic disease, in part reflecting changes in the general living conditions and access to health services of the populations. More recently, evidence has begun to suggest that behavioral profiles of AI/AN communities have followed patterns set earlier by the U.S. population, including a tendency toward sedentary lifestyles, increases in dietary fat, tobacco use, and other behavioral risk factors for chronic disease.

Fortunately, opportunities exist to develop strategies for the prevention and control of the morbidity and mortality associated with chronic illness. There has been a steady increase in the general acceptance of the value of certain health services, and more recently a growing acceptance of the value of preventive services among many AI/AN communities. Community-based health programs (increasingly operated by the Tribes, themselves) have become active in a variety of health areas, and have begun to focus on chronic disease with emphasis on the responsibility of individuals for their own health destiny. Taken together these trends emphasize the importance of and the opportunities to develop strategies to deal more effectively with the spectrum of chronic illness that affects AI/AN communities.

B. The Burden of Cancer

While the overall rates of cancer in AI/AN populations are widely considered to be less than that in the general U.S. population, the rates for certain cancer sites, including stomach, liver, gallbladder, and cervix, exceed the national rates[1]. Unfortunately, our understanding of the impact of cancer on all AI/AN communities is limited, and the frequently cited rates for cancer in AI/AN populations derive largely from the New Mexico Tumor Registry, which includes only AI/AN people in New Mexico and Arizona. Moreover, there is some evidence that cancer rates may vary by ethnicity, genetic stock, geography, and cultural and behavioral factors.[2,3,4] Evidence for variation is spotty and is suggested from isolated studies of specific AI/AN populations (Lanier[5,6]). Thus, our understanding of the patterns of cancer incidence and mortality (and most importantly in the variations therein) in the AI/AN communities throughout the U.S. is incomplete.

Despite suggestions of relatively low occurence rates for cancer in general, the survival experience of AI/AN people who develop cancer is extremely poor (SEER,). The relative proportions of the projected "excess" mortality attributable to behavioral risk factors, pathophysiology of the specific cancers, access to care (screening, diagnostic, and treatment), knowledge and attitudinal factors affecting both personal care patterns (e.g., BSE, smoking) and care seeking behavior are not entirely clear. It is likely, however, that each of these may in some populations contribute to the excessive and avoidable cancer mortality. Also, a clear and consistent relationship has been demonstrated in non-AI/AN populations between socio-economic status and cancer stage at diagnosis as well as with survival corrected for stage at diagnosis.[8,9]

C. Cancer of the Breast and Cervix

There appears to be a particular margin of avoidable mortality in the case of cancer of the breast and cervix, since early detection can lead to virtual cure. There are several widely held beliefs about the patterns of these two cancers in AI/AN women, based largely on a single data set that describes cancer in AI women in New Mexico and Arizona. The following are often (and perhaps erroneously) generalized to all AI/AN women. Compared to non-AI/AN women in the U.S. it is generally held that:

- AI/AN women experience a relatively lower risk for cancer of the breast, and a relatively higher risk for cancer of the cervix (SEER).
- Cancer of the breast tends to be detected at later stages in AI/AN women (Samet[10]).
- Survival following breast and cervical cancer is much poorer for AI/AN women, even when corrected for the later stage at diagnosis (Samet).

D. Policy and Operational Issues

In order to reduce the excessive mortality due to these two cancers, the Indian Health Service and Tribal Programs need better information with which to plan effective emphasis programs. Research is needed in this area to examine the causes for avoidable morbidity and mortality with particular emphasis on developing information for intervention strategy development and implementation.

The current policy issues differ slightly among the two cancer areas. Mortality due to both cancers is preventable, principally through early diagnosis and treatment. For cervical cancer, the Pap smear is widely recognized as cost-effective for early diagnosis, yet there is universal difficulty in reaching the at-risk population with annual screening. For cancer of the breast there are three strategies (i.e., breast self-examination, physician examination, and mammography) for early diagnosis, and debate continues on the most cost-effective strategy or combination of strategies for early diagnosis among AI/AN women.

E. Study Questions

This series of studies was designed to further develop an information base to support rational clinical policy for the prevention of avoidable cancer mortality in AI/AN women. Seven specific study questions are addressed. These include:

1. *Does the incidence of cancer of the breast and cervix vary by major tribal group and by IHS geographic area?* While most studies have generalized from observations of cancer rates in American Indian women in New Mexico and Arizona, it is possible to estimate population rates from existing IHS data sets. Understanding variation in cancer rates is important both in focusing appropriate interventions, as well as in understanding the determinants of avoidable mortality. Baseline estimates of population rates may also assist in evaluating intervention strategies that are subsequently developed and tested.

2. *What is the pathway to diagnosis of breast cancer?* Late diagnosis of breast cancer represents a remediable deficiency in the system of health care for AI/AN women. Understanding the relative contribution cancer diagnosis of both patient and system factors will greatly facilitate development of strategies for diagnosis at early stages.

3. *What are the characteristics of the patients who were diagnosed with late stage breast tumors, compared with patients diagnosed with early stage tumors?* Understanding the risk factors associated with late or delayed diagnosis of breast cancer will suggest target groups for screening emphasis.

4. *What are the risk factors for breast cancer in American Indian women?* While there is much known about the risk factors for breast cancer in non-Indian women, there is virtually no evidence to confirm the same risk factors in AI/AN women. Although the incidence of breast cancer is less than in the general female population of the U.S., many of the established breast cancer risk factors are thought to be relatively more frequent in American Indian women. This study will examine for Indian women the strength of the association of known risk factors as well as other factors potentially predictive of breast cancer in AI/AN women. In addition, this study examines the availability of risk factor data in the patient medical record.

5. *What are the patterns of knowledge, attitudes, and behaviors of American Indian women about cancer of the breast and cervix?* In order to better adapt the clinical approach of the IHS and Tribal programs to the early detection of breast and cervical cancer, it is important to understand the knowledge, attitudes, and (self-reported) behaviors of American Indian women regarding the preventive and early detection strategies, and toward the personal behaviors that can enhance both prevention and early detection for these cancers.

6. *What are the patterns of beliefs, knowledge, and attitudes of the physicians about cancer of the breast and cervix?* It is important to examine factors to which IHS providers ascribe the often seen patterns of late or delayed diagnosis and lack of adequate follow-up of positive screening results?

7. *What are the major strengths and weaknesses in the process of care for early detection of cancer of the breast and cervix?* There are a number of operational challenges in assuring adequate screening for breast and cervical cancer. Both require screening procedures that many women would prefer to put off, neither provide the screening results on the same visit, and thus abnormal results require a second contact with the patient, and both require a secondary procedure in follow-up of positive screening results. In studies of other chronic conditions, it is not surprising that a large number of individuals are screened positive and subsequently fall through the cracks in the system of care.[11,12] By carefully studying the dynamics of the health care system in screening for and following up positive screens for cervical cancer, an important body of information will be gained that will lead to effective interventions to improve the process of care for both cancers, and perhaps for other chronic diseases as well.

F. Overview of the Project Components

This study has been conducted as an integrated series of six separate studies. These include a case-control study of women with breast cancer that addressed questions 2, 3, and 4 above. A population-based cohort study described the natural history of the case finding process for cervical cancer, in turn addressing study question 7. A population-based survey of the knowledge, attitudes, and beliefs of American Indian women regarding cervical and breast cancer would address study question 5. The development of the survey instrument was contracted at the request of the IHS OPEL; the contract has been let and the work is in progress as reported below. A questionnaire survey of IHS physicians examined knowledge of the current screening recommendations and physician perceptions of barriers to complying with those recommendations as in study question 6. Secondary analysis of data from existing IHS data sets has generated more specific estimates of the cervical and breast cancer rates among relevant subsets of AI/AN populations for study question 1. Finally, secondary data was used from both the IHS and national data sets and studies to examine the implications of different strategies for breast cancer screening. Each of the component studies is detailed in the chapters that follow.

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III. CANCER INCIDENCE AND MORTALITY IN AMERICAN INDIAN AND ALASKA NATIVE WOMEN: AN IHS PERSPECTIVE

A. Introduction

Although American Indians and Alaska Natives (AI/AN) are considered to be low-risk populations for cancer compared to the general population, the impact of certain cancer sites is out of proportion to its occurence. For example, southwestern tribes experience excessive mortality associated with breast cancer despite incidence rates that are one-third to one-half the rate for the general population[1]. It is known that when breast cancer is diagnosed in some populations, it is at a more advanced stage, and that survival rates are below non-Indian patients, even when controlled for diagnostic and treatment factors.[2] The unfavorable survival is probably due to multiple factors, and some may be amenable to change in the patterns of care provided by the IHS and tribal programs.

Limited data are available to describe the cancer experience among AI/ANs. Most of our knowledge of the epidemiology of cancer in Indian people comes from the New Mexico Tumor Registry. Early studies from this SEER site suggest that cancer incidence and mortality in southwest Indians is less than that of the general population.[1] Recent studies report geographical and tribal variations in incidence, such as higher than expected rates of cervical cancer in Pacific Northwest Indians[3], and increased rates of the nasopharynx, salivary gland, liver, gallbladder and uterine cervix in Alaska Native women[4], compared to the U.S. general population.

In order to expand our knowledge of invasive cancer in AI/AN women this study uses existing data sets to describe the incidence and mortality for seven cancer sites during the 1980's. Variation among rates by IHS Area of residence and tribal affiliation are the focus of this report.

B. Methods

In order to estimate IHS Area of residence- and tribal-specific incidence rates for selected cancer sites, cases were identified using the IHS Direct and Contract Inpatient database. This data set is managed by the Division of Program Statistics of the IHS. All IHS direct and contract hospitals report to this system with the exception of the California Area and tribally-operated hospitals; consequently these facilities are not represented in this report.

Each record within the Inpatient Reporting System represents a discharge rather than a unique patient. In order to identify individual cancer patients, an algorithm was developed to unduplicate total cancer site-specific admissions down to the individual level. Combinations of the following demographic information were used for the unduplication process: IHS chart number; social security number, when available; community of residence; date of birth; and date of admission. To include only newly diagnosed or "incident" cancer cases during the study period, the calender years, 1980-1981 were used to screen out previously diagnosed or "prevalent" cases from the cancer site-specific "incident" cohorts. For example, for each specific cancer site, a patient who had an admission in 1982-1987, as well as admission in 1980-1981 was considered to be a "prevalent" case and excluded from analysis. Therefore, this study's definition of an "incident" case is an individual's first hospital admission in 1982-1987 with an ICD-9[5] coded discharge di-

agnosis for the following cancer sites: breast, uterine cervix, endometrium, ovary, genital, lung/bronchus, colorectal and allsites (Table 1).

Table 1
ICD-9 Codes for Selected Cancer Sites

Site	ICD-9 Codes	Site	ICD-9 Codes
Breast	174.0-174.9	Lung/Broncus	162.2-162.5
Cervix	180.0-180.9		162.8-162.9
Endometrium	182.0	Colon/Rectum	153.0-154.9
Ovary	183.0	All Sites	140.0-195.5
Genital	179.0-184.9		199.0-208.9
			233.7

Denominators used to describe the population at risk for calculation of incidence rates, were based upon Service Population estimates derived from the 1980 Census.[6] To correct for the exclusion of tribally-operated hospitals, their respective Service Populations were subtracted from Area total populations. Most Area Service Populations were not greatly affected by these adjustments with the exception of Nashville and Bemidji Areas, where most inpatient services are provided by tribal programs and consequently, are not tracked by the IHS Inpatient Database System. Specifically, the Cherokee Service Unit is Nashville's only Service Unit represented in the IHS Inpatient System and accounts for only 25% of Nashville's Service Population. Likewise, in Bemidji the three non-tribal Service Units (Greater Leech Lake, Red Lake, and White Earth) account for less than one-third of the total Service Population. The Portland Area's total Service Population was believed to be a gross overestimation, due mainly to the large numbers of eligible Indians estimated to be living in Western Oregon and Puget Sound Service Units. In order to estimate incidence rates for Portland Area, we excluded both Western Oregon and Puget Sound cases and Service Populations from the numerator and denominator. Table 2 lists the adjusted denominators used in calculation of incidence rates by IHS Area.

Table 2
Female Years at Risk Used in Calculation of Area-Specific Incidence Rates, IHS Inpatient Database, 1982-1987

Area	Female Years at Risk
Aberdeen	217,819
Alaska	168,673
Albuquerque	160,187
Bemidji	41,780
Billings	127,445
Nashville	22,785
Navajo	508,391
Oklahoma	551,717
Phoenix	255,523
Portland	139,126
Tucson	53,826
All Areas	2,247,282

In this study incidence rates were estimated for the following selected tribes who reside in their historical North American homelands based upon present-day IHS Area of residence: Aleut/Alaska; Apache/Albuquerque & Phoenix; Eskimo/Alaska; Navajo/Navajo; Sioux/Aberdeen; and Pima-Tohono O'Odham/Phoenix and Tucson. The Apache tribe includes White River Apaches, San Carlos Apaches, Jicarillo Apaches, and the Mescalero Apaches. The Tohono O'Odham and Pima tribes were considered to be anthropologically homogenous (i.e., genetically, culturally, linguistically, and geographically), therefore, these two tribes were combined for the purposes of this study. Numerators for tribal rates were based on tribal affiliation codes included in the IHS Inpatient System and the patient's Area of residence at the time of the initial cancer diagnosis. For example, a woman identified as Navajo must have also resided in the Navajo Area, all Navajos living in other Areas were excluded from analysis. Denominators used to describe the number of women at risk for specific tribes were based on 1980 Census data[7,8] and the patient's Area of residence. For example, each of the tribes are, in general, from geographically defined IHS Areas or an aggregate of counties within specific Areas. In order to estimate the number of tribal members within a specific Area, tribal-specific counts for counties which make up the Areas were summed to estimate the population at risk. Table 3 shows the total female years at risk for the six-year incidence study period and lists the area of residence for each tribe.

Table 3
Female Years at Risk Used in Calculation of Selected Tribal-Specific Incidence Rates and Area of Residence, 1982-1987

Tribe	Female Years at Risk	Area
Aleut	22,098	Alaska
Apache	63,906	Phoenix/Albuqurque
Eskimo	93,258	Alaska
Navajo	449,094	Navajo
Sioux	136,740	Aberdeen
Tohono O'Odham/Pima	72,060	Tucson/Phoenix

Average annual incidence rates were based upon six years of cases and female years at risk for the six year study period. Rates were age-adjusted using the Direct Method with the 1970 U.S. female population as standard. For each estimated rate, a ninety-five percent confidence interval has been constructed and reported.[9] The confidence interval ranges reflect the observed standard error of the estimated rate. For rates estimated with a small number of cases as the numerator value, the estimated variance and associated standard error will be quite large. Such a situation could result in the lower bound of the confidence interval estimate being negative. Given that negative rates are not interpretable, a negative lower bound was truncated to zero.

The National Center for Health Statistics (NCHS) American Indian and Alaska Native Mortality Detail Database was used to identify AI/AN women whose underlying cause of death was ICD-9 coded to one of the selected cancers sites under study.

For the purposes of this study, certain criteria were used to determine Areas for which mortality rates might best reflect the actual cancer-related death experience among AI/AN women geographically eligible for services provided by the IHS. For reservation states to be

included in Area-specific mortality rates, the AI/AN Service Population must have accounted for at least 80% of the state-wide total AI/AN population. For states which met the 80% Service Populatation criteria, the total AI/AN female population was used as the denominator in the calculation of mortality rates regardless of IHS eligibility status. Table 4 shows the female years at risk by IHS Area and lists states which accounted for area population estimates. For comparative purposes, rates for the U.S. All Races Female were reported from NCHS's Surveillance, Epidemiologic End Results Program.[10]

Table 4
Female Years at Risk Used in Calculation of Selected Area-Specific Mortality Rates, AI/AN Mortality Detail File, 1980-1986

Area/States	Female Years at Risk[1]
Aberdeen North Dakota South Dakota	257,166
Alaska Alaska	246,477
Billings Montana	152,943
Oklahoma Oklahoma	662,165
Portland Oregon Washington	337,596
Southwest Arizona New Mexico Nevada	1,084,405
TOTAL	2,740,752

[1]Years at risk include total AI/AN female population living in states regardless of IHS eligibility status.

C. Results

1. Area Incidence Rates

During the time period 1982 to 1987, 2,670 incident hospitalizations for invasive neoplasms were identified among AI/AN women admitted to non-tribally operated direct and contract IHS hospitals. Table 5 shows the number of cases identified for selected cancers by IHS Area.

TABLE 5

Number of Incident Cases of Select Cancer Sites Identified for AI/AN Women Admitted Non-tribally operated IHS Direct and Contract Hospitals by Area of Residence, IHS Inpatient Database, 1982-1987.

Area	Breast	Cervical	Endometrial	Ovarian	Genital	Lung Bronchus	Colorectal	All Sites
Aberdeen	57	36	9	11	60	35	19	266
Alaska	61	33	2	14	54	48	69	338
Albuquerque	19	27	4	12	44	9	14	161
Bemidj	4	2	1	0	3	11	9	48
Billings	29	25	7	12	45	25	9	162
Nashville	6	3	1	3	8	4	4	38
Navajo	77	78	13	30	127	9	24	486
Oklahoma	137	55	33	32	128	53	84	586
Phoenix	33	35	24	15	80	16	18	264
Portland	14	9	6	6	28	7	16	115
Tucson	6	7	9	3	17	2	2	49
TOTAL	481	325	113	148	613	236	268	2,670

Age-adjusted incidence rates based on Area of residence varied markedly among regions for selected cancer sites (Table 6). Figures 1a-h show relative incidence rate differences among IHS Areas according to type of cancer. AI/AN rates and U.S. rates are standardized to per 100,000 female years at risk and per 100,000 female population, respectively. Cautious interpretation of observed relative differences is advised due to small numbers.

a. Breast

The overall IHS rate of breast cancer was one-third the rate for U.S. All Races Female (32.4 vs. 97.0). The Alaska Area had the highest rate (59.5) while the Tucson Area had the lowest (15.2). The 1982-1987 rate in all Southwest IHS Areas was less than 26. It is of interest that the three highest rate Areas (Alaska, Aberdeen, and Billings) are the Northern most regions of the IHS, although two other northern tier Areas have relatively low observed rates (Figure 1a).

b. Cervix

The overall IHS rate of invasive cervical cancer was almost two and a half times the rate for U.S. All Races (20.2 vs. 8.8), with all Areas exceeding the U.S. rate. Billings, Alaska, Albuquerque had the highest rates while Bemidji, Oklahoma and Portland were the lowest rate Areas (Figure 1b).

c. Endometrium

Cancer of the edometrium among all AI/AN women occurred at one-third the rate for the U.S. All Races. However, the rate of endometrial cancer in the Tucson Area is strikingly high relative to other IHS Areas and nearly equals the U.S. rate (22.1 vs. 22.6, respectively) (Figure 1c).

d. Ovary

The incidence of ovarian cancer in four IHS Areas (Nashville, Billings, Albuquerque, and Alaska) exceeded the U.S. All Races rate while the incidence rates for the Portland and Oklahoma Areas are markedly lower than the U.S. rate (Figure 1d).

e. Genital

The Billings Area had an incidence rate for all invasive cancers of the female genital system substantially higher than the U.S. All Races rate. Seven areas had rates comparable to the the U.S. rate: Albuquerque, Alaska, Nashville, Tucson, Aberdeen, Phoenix and Navajo. Oklahoma had an incidence rate substantially below the national average for female genital cancer (Figure 1e).

f. Lung/Bronchus

Three Areas (Bemidji, Alaska, and Billings) had rates higher than the Female U.S. All Races incidence rate for cancer of the lung or broncus. Aberdeen and Nashville had rates intermediate between the U.S. All Races and IHS All Areas rates. Rates from the Southwest Areas were lowest, as were rates for the Portland and Oklahoma Areas (Figure 1f).

TABLE 6

Average Annual Age-Adjusted[1] Incidence Rates (per 100,000 female years at risk) and 95% Confidence Intervals[2] for Selected Cancer Sites by Area of Residence for American Indian and Alaska Native Women Admitted to Non-Tribally Operated IHS Direct and Contract Hospitals, 1982-1987

Area	Breast	Cervical	Endometrial	Ovarian	Genital	Lung Bronchus	Colorectal	All Sites
Aberdeen	44.9 [32.5,57.3]	23.5 [15.3,31.7]	7.6 [2.4,12.8]	10.2 [4,16.4]	44.5 [32.5,56.5]	31.1 [20.4,41.8]	17.9 [9.3,25.5]	215.0 [187.7,242.3]
Alaska	59.5 [42.7,76.8]	28.5 [17.9,39.1]	3.4 [0,7.3]	14.3 [6.1,22.5]	46.8 [33.2,80.4]	52.3 [36.6,88]	85.1 [63.8,106.6]	362.2 [320.4,404]
Albuquerque	20.2 [10.2,30.2]	28.1 [16.6,39.8]	35.3 [0,6.8]	15.3 [5.9,24.7]	48.8 [33.1,64.5]	11.9 [3.8,20]	19.1 [8.4,29.8]	192.1 [159.8,224.4]
Bemidj	17.1 [0,35.9]	8.6 [0,21.9]	2.3 [0.7]	- [ ]	10.9 [0,25]	53.7 [21.1,86.4]	42.31 [13.4,71.3]	210.4 [146.5,274.7]
Billings	38.6 [23.5,53.7]	19.6 [18.3,45.5]	10.4 [2.4,18.4]	18.3 [7.5,29.2]	62.1 [52.8,81.8]	40.1 [23.8,56.4]	15.9 [5.3,26.6]	223.7 [186.8,261]
Nashville	33.5 [5.5,61.5]	16.8 [0,36.6]	6.4 [0,19.3]	19.3 [0,41.6]	46.4 [13,79.8]	28.1 [0,56.1]	23.2 [0,46.8]	213.7 [142.3,285.5]
Navajo	25.9 [19.7,32.2]	24.8 [18.8,30.9]	3.8 [1.6,6]	10.5 [6.4,14.6]	40.7 [33,48.6]	3.9 [1.3,6.4]	8.3 [4.7,11.9]	167.7 [151.7,184.1]
Oklahoma	29.8 [24.7,35]	11.4 [8.3,14.3]	7.3 [4.9,9.7]	6.9 [5.4,8.1]	26.2 [21.6,30.8]	11.8 [8.3,15]	18.9 [14.7,23.2]	122.8 [112.6,133]
Phoenix	18.1 [11.5,24.8]	19.3 [12.3,26.4]	11.1 [6.4,15.9]	9.0 [4,14.1]	42.8 [37.6,4]	11.1 [5.8,17.6]	13.5 [7,20.1]	156.6 [136.2,177.4]
Portland	18.9 [8.5,29.3]	13.3 [4.2,22.5]	7.9 [1.2,14.5]	6.3 [0.7,12]	28.8 [17.2,40.6]	9.5 [2.3,18.6]	21.8 [10.5,33.2]	139.2 [111.9,186.8]
Tucson	15.2 [2.2,28.2]	19.7 [3.9,36.6]	22.1 [6.4,37.8]	8.9 [0,19.6]	45.7 [21.6,69.8]	7.6 [0,18]	8.2 [0,19.6]	156.6 [108.6,204.6]
All Areas	32.7 [29.6,35.9]	20.1 [917.7,22.3]	7.2 [5.8,8.6]	10.4 [8.6,12.2]	39.3 [36,42.6]	18.2 [15.8,20.6]	21.2 [18.4,23.8]	188.0 [180.4,195.6]
US All Races[3] Female	97.0	8.8	22.6	13.5	47.9	34.4	32.4/11.4[4]	323.4

[1] 1970 U.S. Female population used as standard.

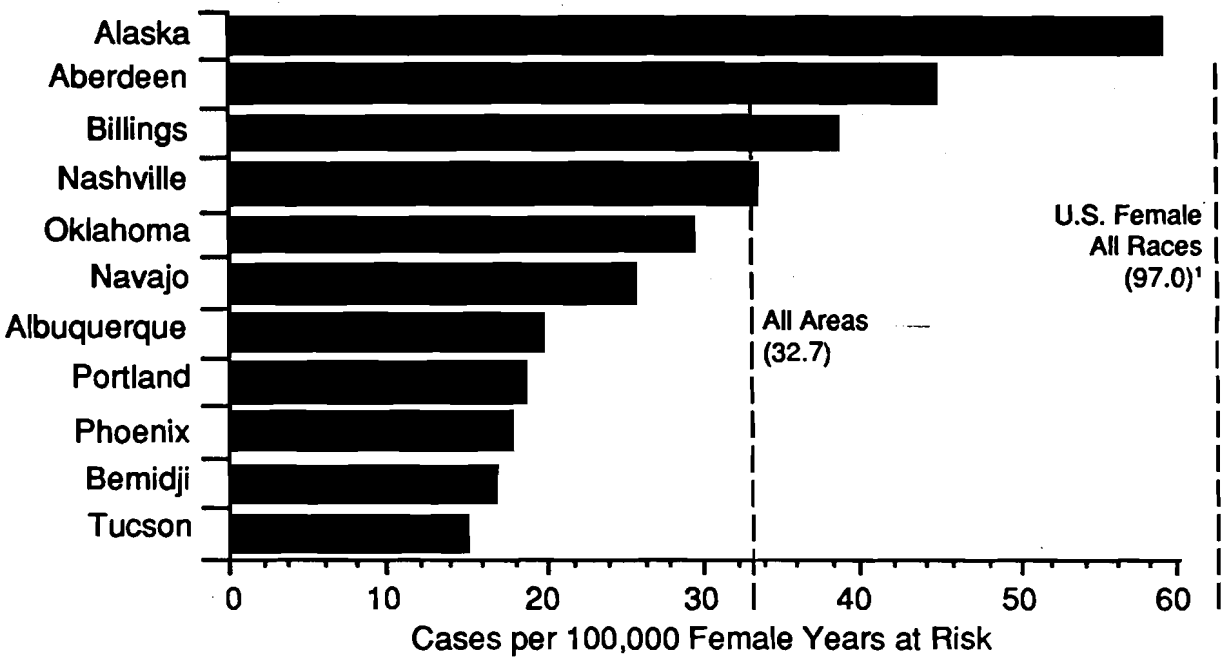
[2] SEER, 1982-1986

[3] SEER reports colon and rectum separately: colon/rectum

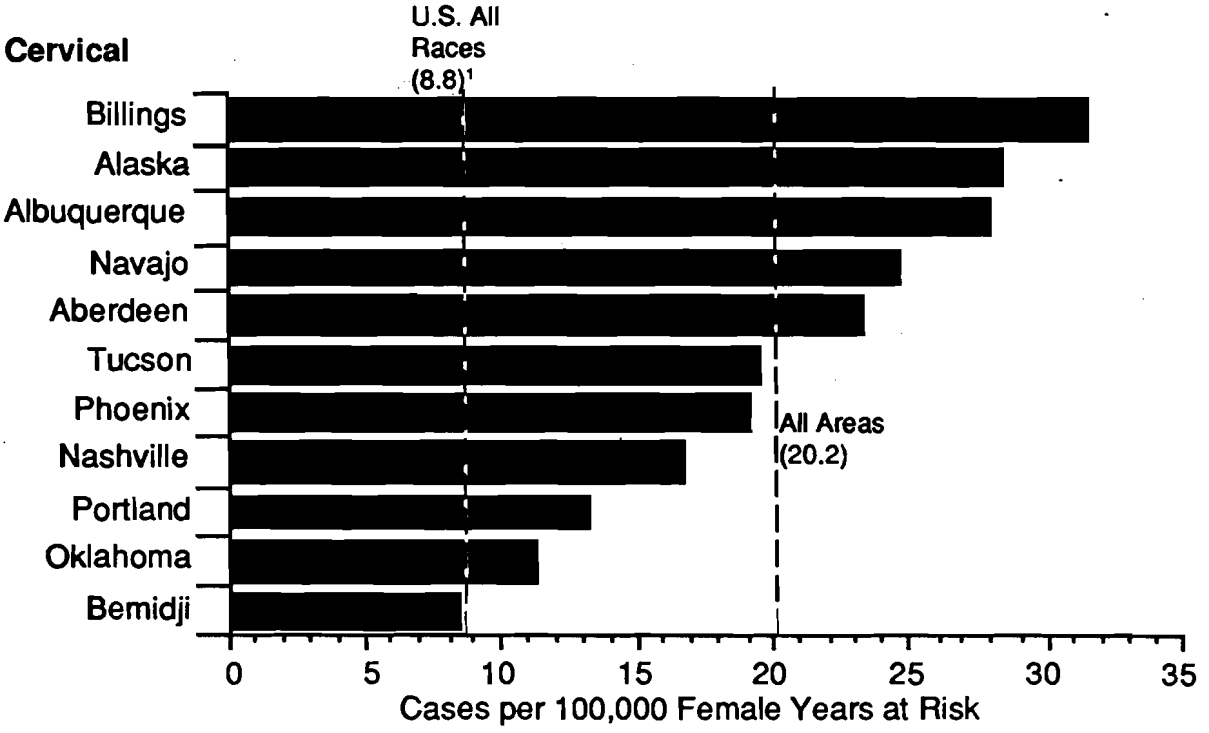
[4] SEER reports colon and rectum sepazrately: colon/rectum

Figures 1a-1h: Relative Age Adjusted Incidence Rates by IHS Area of Residence for Selected Cancer Sites Among American Indian and Alaska Native Women Admitted to Non-Tribally Operated IHS Direct and Contract Hospitals, 1982-1987

1a) Breast



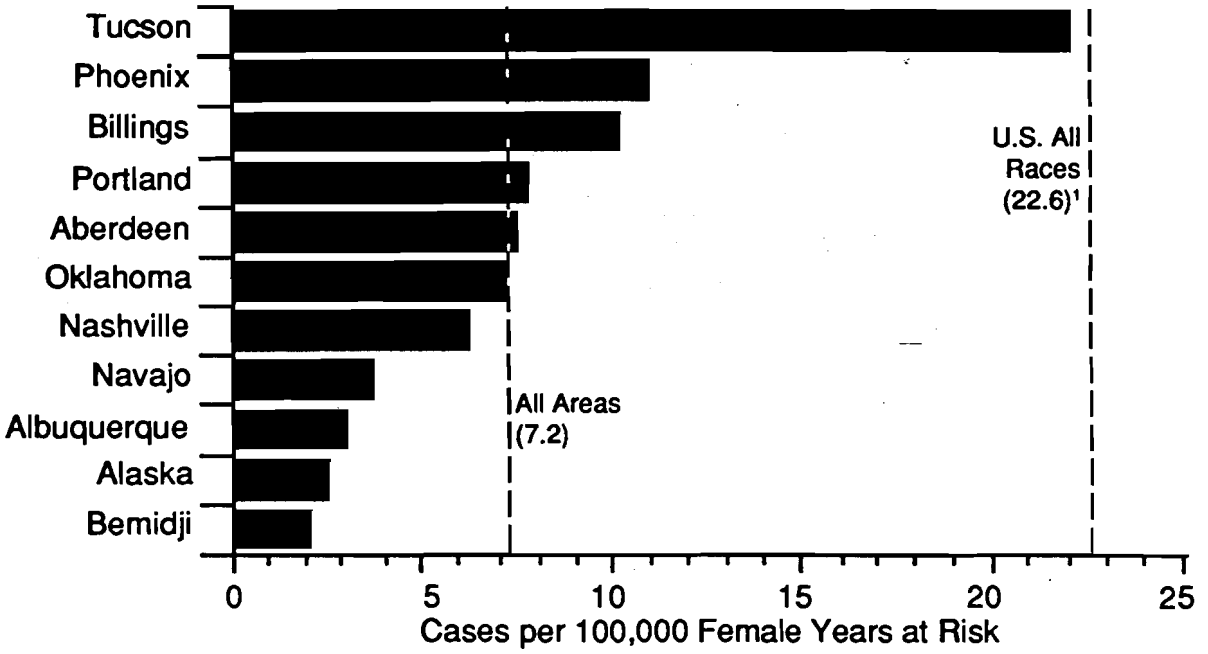
1b) Cervical



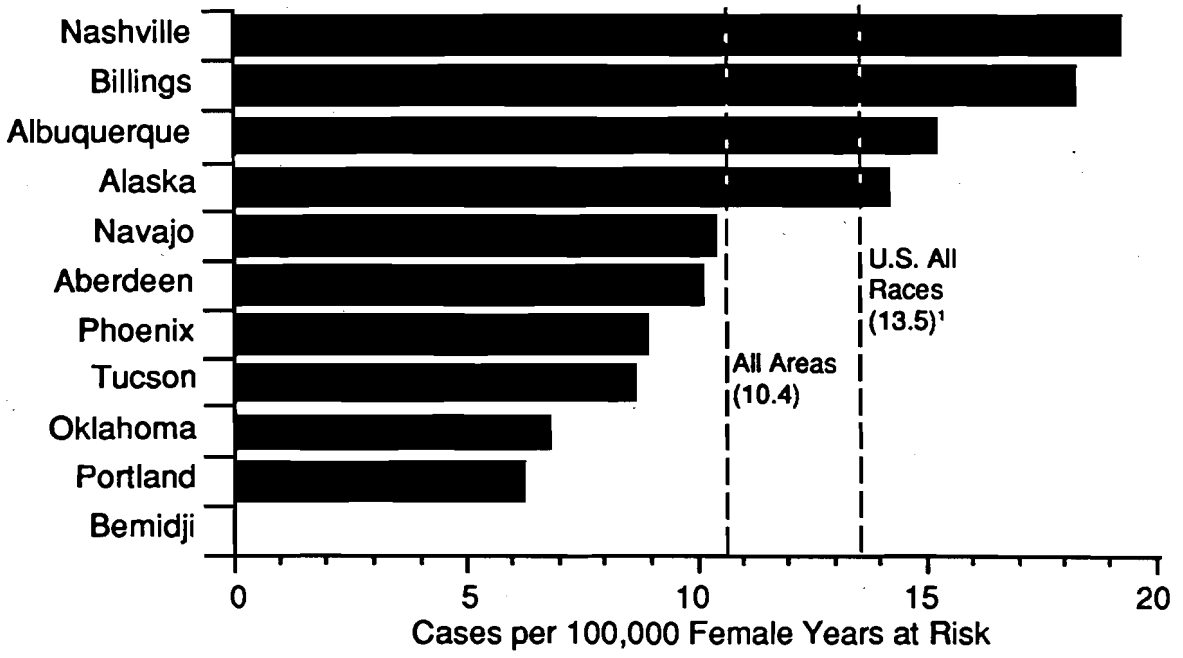
[1]SEER: 1982-1986

Figures 1a-1H: Incidence Rates by IHS Area of Residence (Continued)

1c) Endometrium



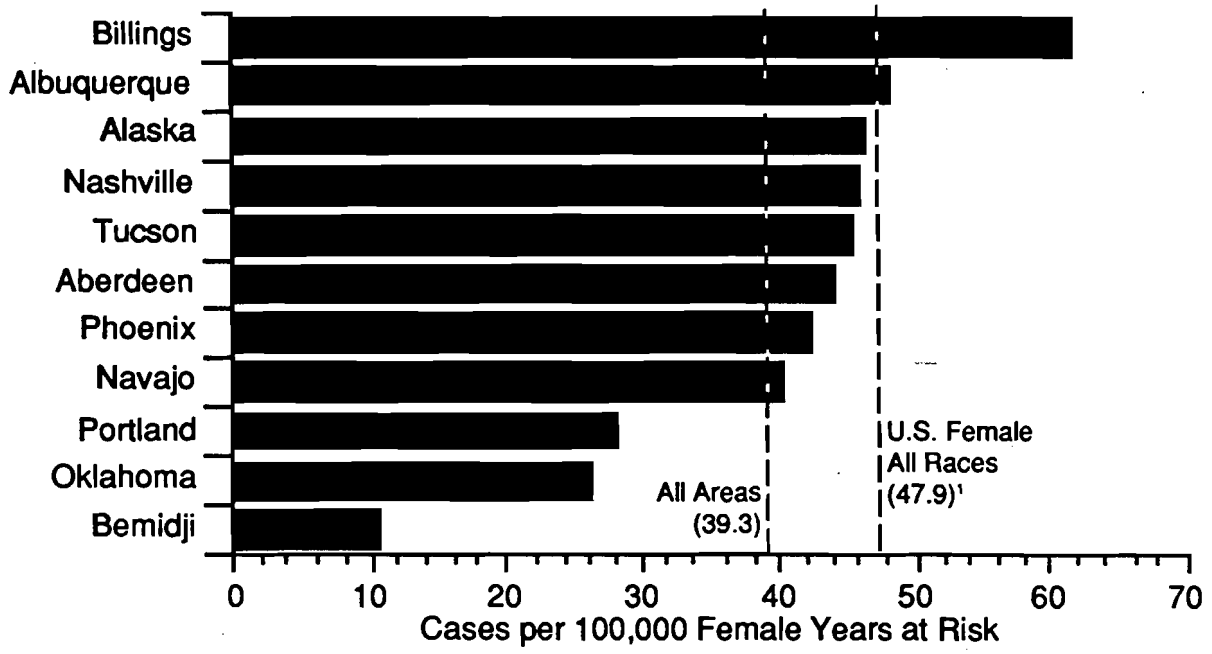
1d) Ovarian



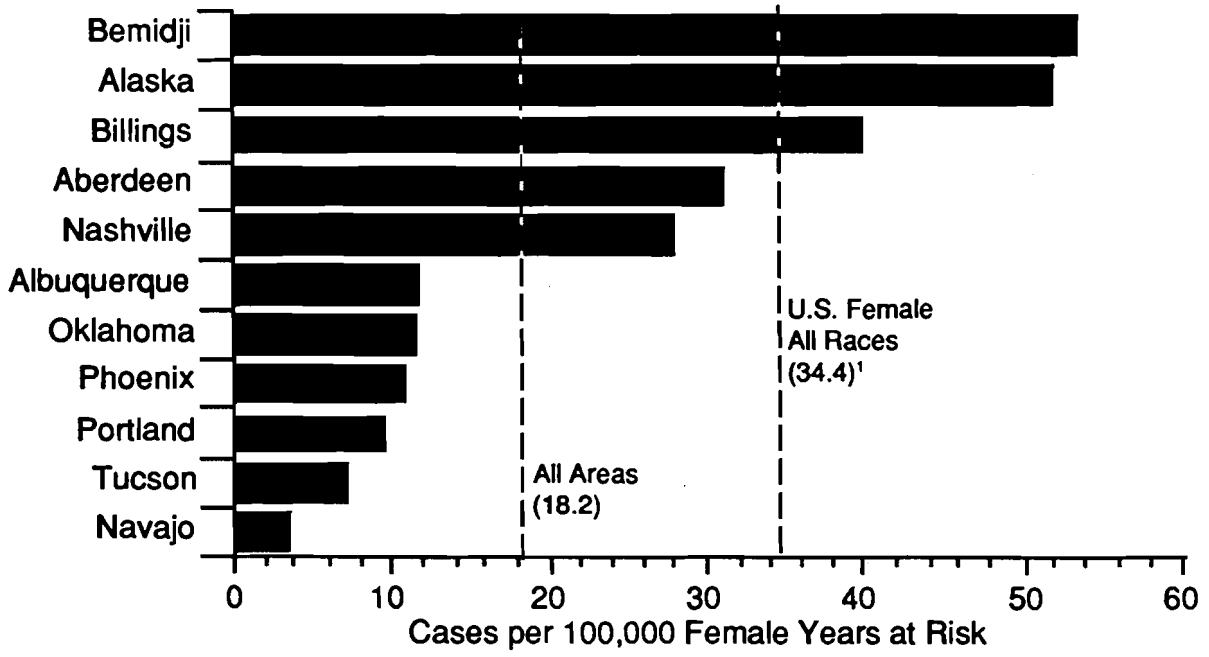
[1]SEER: 1982-1986

Figures 1a-1h: Incidence Rates by IHS Area of Residence (Continued)

1e) Genital



1f) Lung/Bronchus



[1]SEER: 1982-1986

g. Colorectal

Alaska Area had a strikingly high incidence of cancer of the colon and rectum relative to national averages and other IHS Areas while the Tucson and Navajo Areas had the lowest rate for these two combined cancer sites (Figure 1g).

h. All Sites

The U.S. Female All Races overall invasive cancer incidence rate is substantially higher compared to the IHS overall rate (323.4 vs. 188.0, respectively). The Alaska Area is the only IHS Area with an allsites cancer rate which exceeds the U.S. national average (Figure 1h).

2. Tribal Incidence Rates

Tribal-specific rates varied markedly for most selected cancer sites. Table 7 shows the actual number of cancer cases by tribe. Tribal-specific rates are shown in Table 8. Figures 2a-h illustrate relative differences among tribes for each cancer site. Cautious interpretation of observed relative differences is advised due to small numbers.

a. Breast

The Eskimo and Sioux tribes had the highest incidence rates for invasive cancer of the breast while the Tohono O'Odham/Pima, Navajo and Apache tribes had the lowest rates (Figure 2a).

b. Cervix

Cervical cancer incidence rates for the selected tribes all exceeded the U.S. All Races Female rate. Little variation in the occurence of this cancer was observed among the six tribes (Figure 2b).

c. Endometrium

The extremely high rate of endometrial cancer for the Tohono O'Odham/Pima Indians living in the Tucson and Phoenix Areas is even more striking than the Tucson Area rate. No cases of endometrial cancer were identified during the six year study period for the Aleuts from Alaska (Figure 2c).

d. Ovary

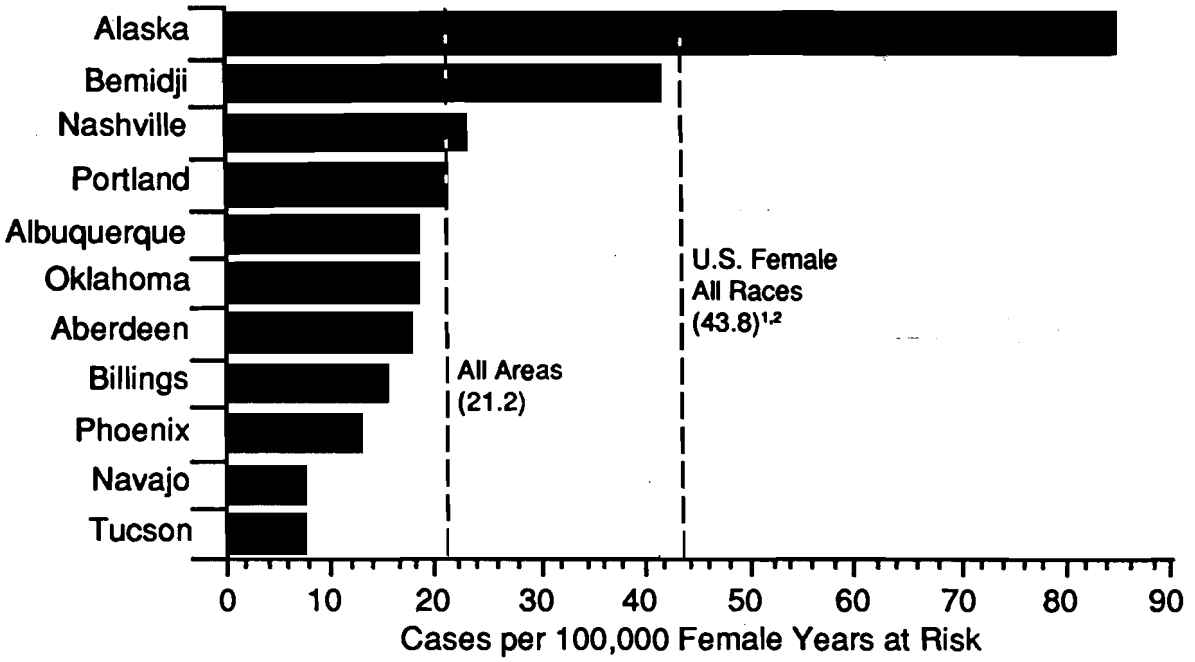
The highest rate of ovarian cancer among the six tribes occurred in the Apaches of Phoenix and Albuquerque. The Apache and Aleut incidence rates were comparable to the U.S. All Races rate (15.0 and 13.3 vs. 13.5, respectively) (Figure 2d).

e. Genital

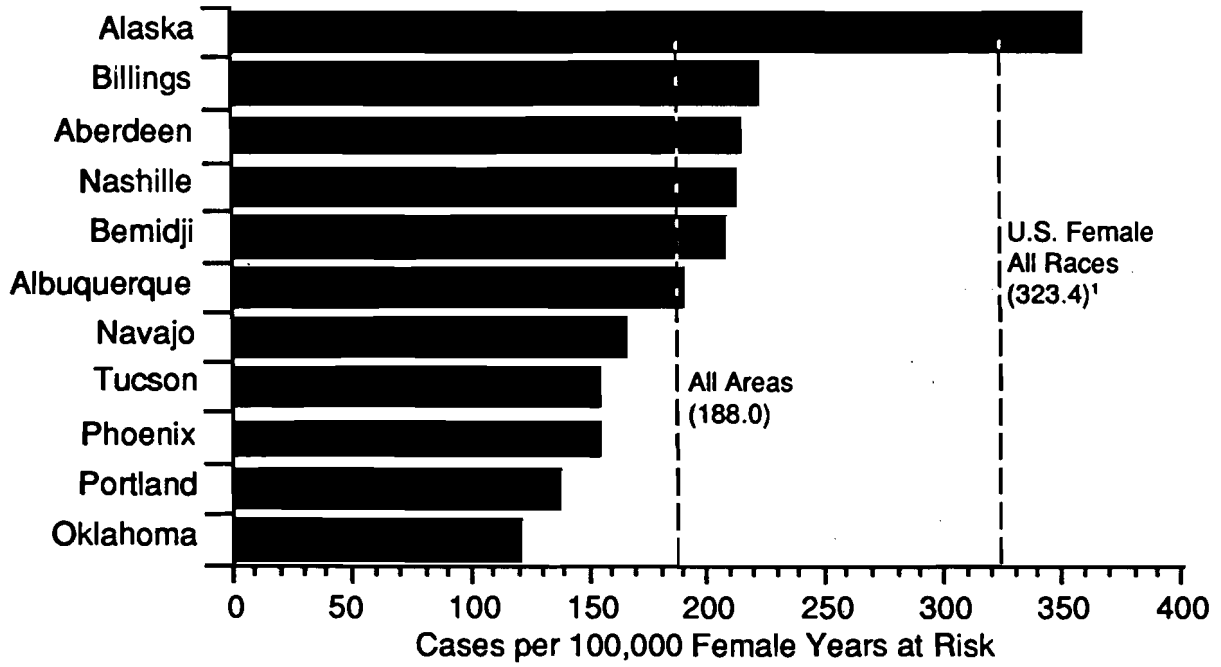
Four of the six tribes (Tohono O'Odham, Sioux, Apache, and Eskimo) had incidence rates higher than the U.S. All Races with the Tohono O'Odham/Pima having the highest rate of cancer of the female genital system (Figure 2e).

Figures 1a-1h: Incidence Rates by IHS Area of Residence (Continued)

1g) Colon/Rectal



1h) All Sites



[1]SEER: 1982-1986
[2]Colon and Rectum Rates were summed for purposes of comparison.

TABLE 7

Number of Incident Cases for Selected Cancer Sites by Patients' Tribal Affiliation, IHS Inpatient Database, 1982-1987

Tribe	Breast	Cervical	Endometrial	Ovarian	Genital	Lung Bronchus	Colorectal	All Sites
Aleut	4	4	0	1	5	11	12	50
Apache	11	15	3	7	27	4	3	79
Eskimo	34	20	2	6	32	24	49	197
Navajo	75	76	16	31	126	9	26	481
Sioux	42	28	8	9	48	24	13	208
Tohono O'Odham/Pima	9	12	18	5	34	5	2	95

TABLE 8

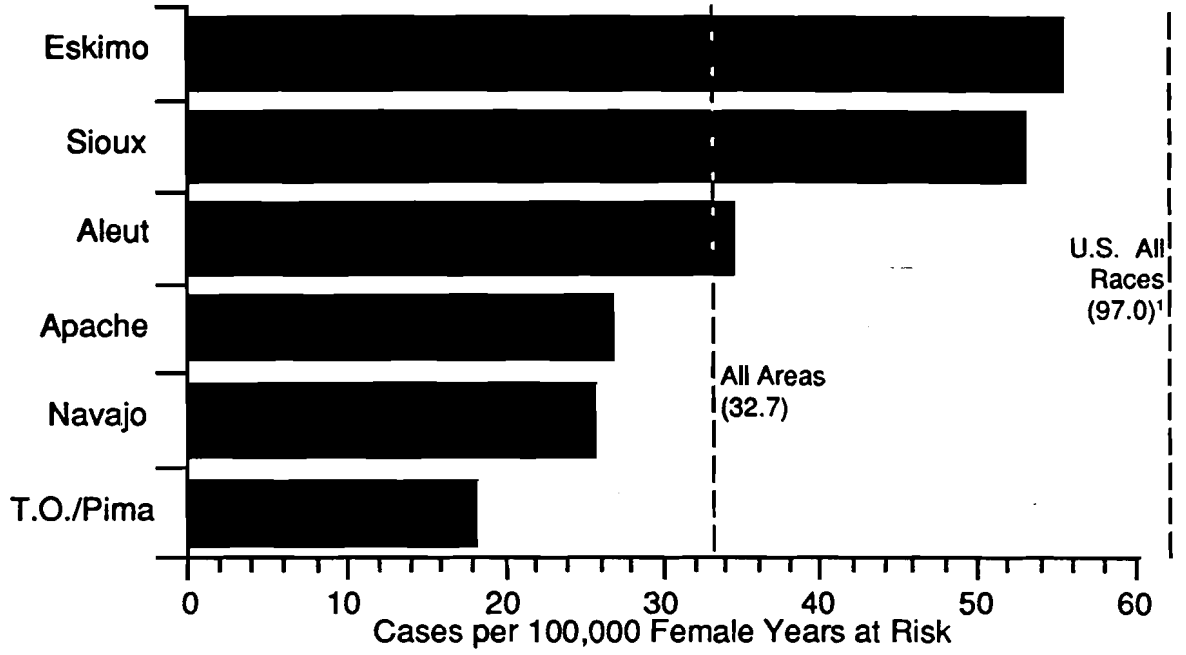
Average Annual Age-Adjusted Incidence Rates[1] (per 100,000 female years at risk) and 95% Confidence Intervals[2] for Selected Tribes Among American Indian and Alaska Native Women Admitted to Non-Tribally Operated IHS Direct and Contract Hospitals, 1982-1987

Tribe	Breast	Cervical	Endometrial	Ovarian	Genital	Lung Bronchus	Colorectal	All Sites
Aleut	34.9 [0,443.3]	26.1 [0,89.8]	0 [ ]	13.3 [0,84.9]	37.5 [0,131.5]	90.8 [0,231.5]	107.6 [0,263.3]	394.9 [107.8,682]
Apache	26.9 [0,67.9]	30.1 [0,70.9]	5.6 [0,22.9]	15.0 [0,45.7]	53.5 [0,108.2]	10.8 [0,38]	8.1 [0,31.3]	179.7 [73.6,285.8]
Eskimo	55.9 [5.5,106.4]	29.7 [0,64.2]	4.1 [0,17.5]	11.4 [0,36.4]	48.2 [25.5,70.9]	47.2 [0,97.4]	100.6 [168.4,148.6]	379.7 [237.8,521]
Navajo	25.8 [10.3,41.3]	24.7 [9.8,39.6]	4.9 [0,11.4]	11.0 [0.5,21.5]	41.2 [21.7,60.7]	4.0 [0,10.6]	9.2 [0,18.7]	172.4 [131.2,213.6]
Sioux	53.5 [11.4,95.6]	28.3 [0.7,55.9]	11.5 [0,32.9]	11.8 [0,31]	56.0 [14.7,97.3]	32.5 [0,66]	18.5 [0,43.9]	266.8 [172.2,361.4]
Tohono O'Odham/Pima	18.3 [0,49.6]	23.3 [0,59.1]	31.9 [0,70.3]	10.7 [0,35.6]	66.4 [6,126.8]	13.7 [0,43.3]	6.1 [0,29.6]	222.1 [108.4,340.6]
IHS All Areas	32.7 [29.6,35.9]	20.2 [17.7,22.3]	7.2 [5.8,8.6]	10.4 [8.6,12.2]	39.3 [36.0,42.6]	18.2 [15.8,20.6]	21.2 [18.4,21.8]	188.0 [180.4,195.6]
US Female - All Races[3]	97.0	8.8	22.6[4]	13.5	47.9	34.4	32.4/22.4[5]	323.4

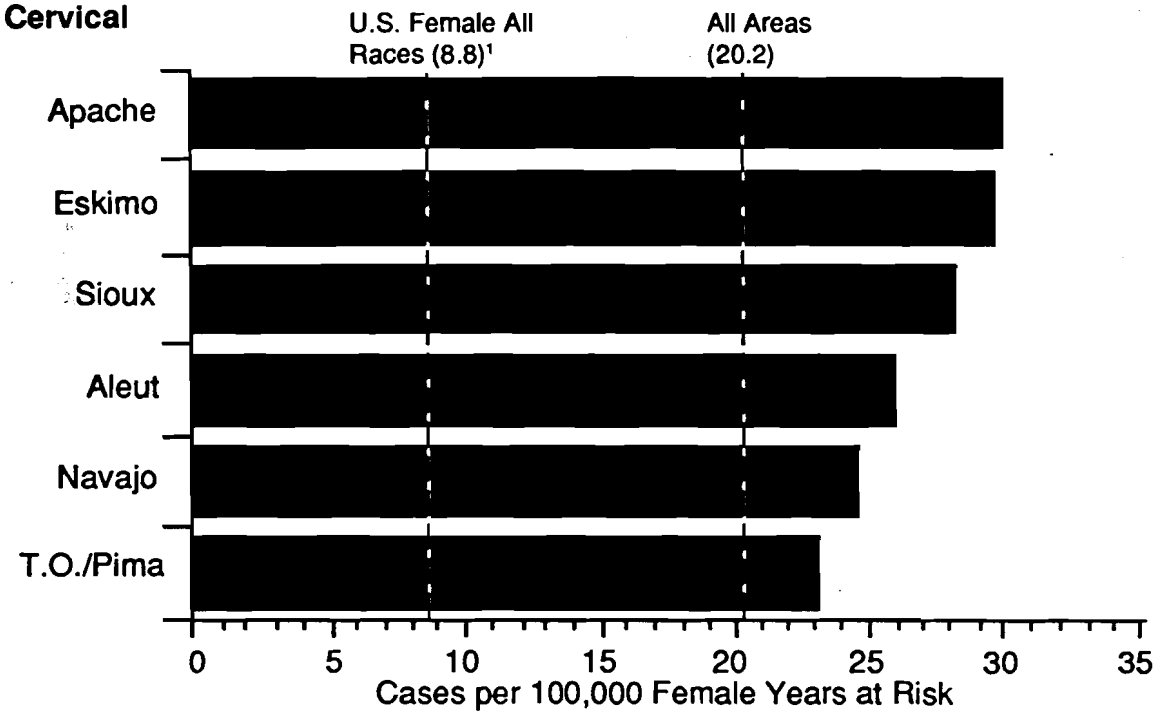
[1]1970 U.S. Female population used as standard
[2]The lower bounds of confidence intervals which were negative have been truncated to zero
[3]SEER, 1982-1986
[4]SEER reports corpus uteri, NOS
[5]SEER reports colon and rectum cancer separately: colon/rectum

Figures 2a-2h: Relative Age-Adjusted Incidence Rates by Tribal Affiliation for Selected Cancer Sites Among American Indian and Alaska Native Women Admitted to Non-Tribally Operated IHS Direct and Contract Hospitals, 1982-1987

2a) Breast



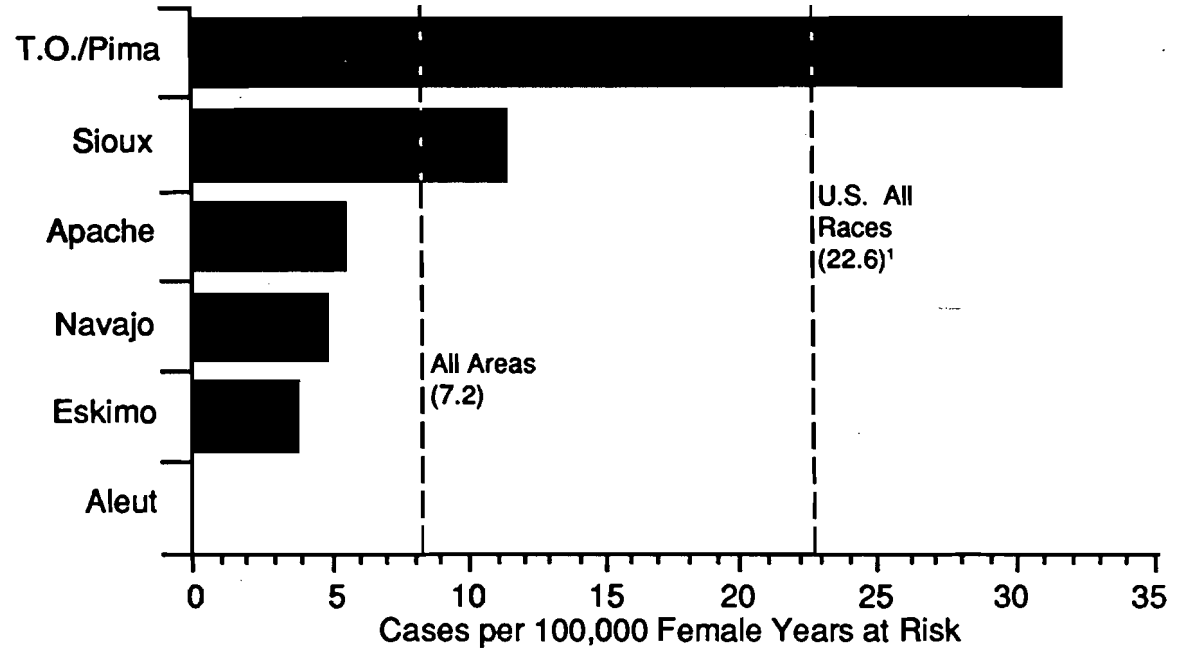
2b) Cervical



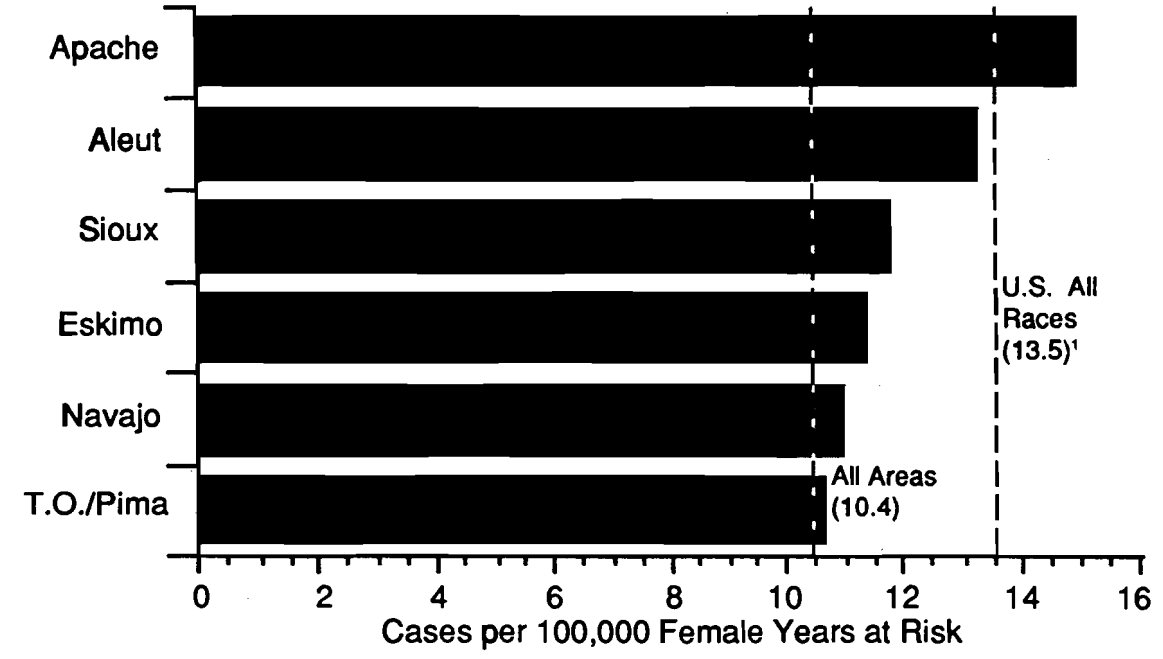
[1]SEER: 1982-1986

Figures 2a-2h: Incidence Rates by Tribal Affiliation (Continued)

2c) Endometrium



2d) Ovarian



[1]SEER: 1982-1986

f. Lung/Bronchus

The Aleuts had an incidence of lung/bronchus cancer nearly three times that of the national average for All Races Females. The Eskimos also had a rate that exceeded the U.S. rate. The three southwestern tribes (Navajo, Apache, and Tohono O'Odham) had rates less than half the U.S. rate (Figure 2f).

g. Colorectal

Both Alaska Area tribes, Eskimo and Aleut, had colorectal rates which were more than two-fold the U.S. Female All Races rate for colon cancer (Figure 2g).

h. All Sites

The all Sites invasive cancer incidence rates for the Aleut and Eskimo tribes exceeded the U.S. Female All Races rate (394.9 and 379.7 vs. 323.4, respectively). The other four tribes had all sites cancer rates below the national average. The Navajo and Apache tribes had overall cancer rates below the overall IHS incidence rate (Figure 2h).

3. Area Mortality Rates

During the time period 1980 to 1986, 1,870 cancer-related deaths were identified for AI/AN women who had resided in selected states in which at least 80% of the AI/AN population was geographically eligible for IHS services (Table 9). Mortality rates appear to vary between AI/AN women compared to U.S. All Races Females and across IHS Areas for selected cancer sites (Table 10). Figures 3a-h illustrate relative death rates among selected IHS Areas. Cautious interpretation of observed relative differences is advised due to small numbers.

a. Breast

Mortality rates associated with breast cancer by IHS Area ranged from nearly one-third to two-thirds the U.S. Female All Races death rate (27.1). Aberdeen Area had the highest mortality rate with Portland Area having the lowest (17.0 vs. 8.1) (Figure 3a).

b. Cervix

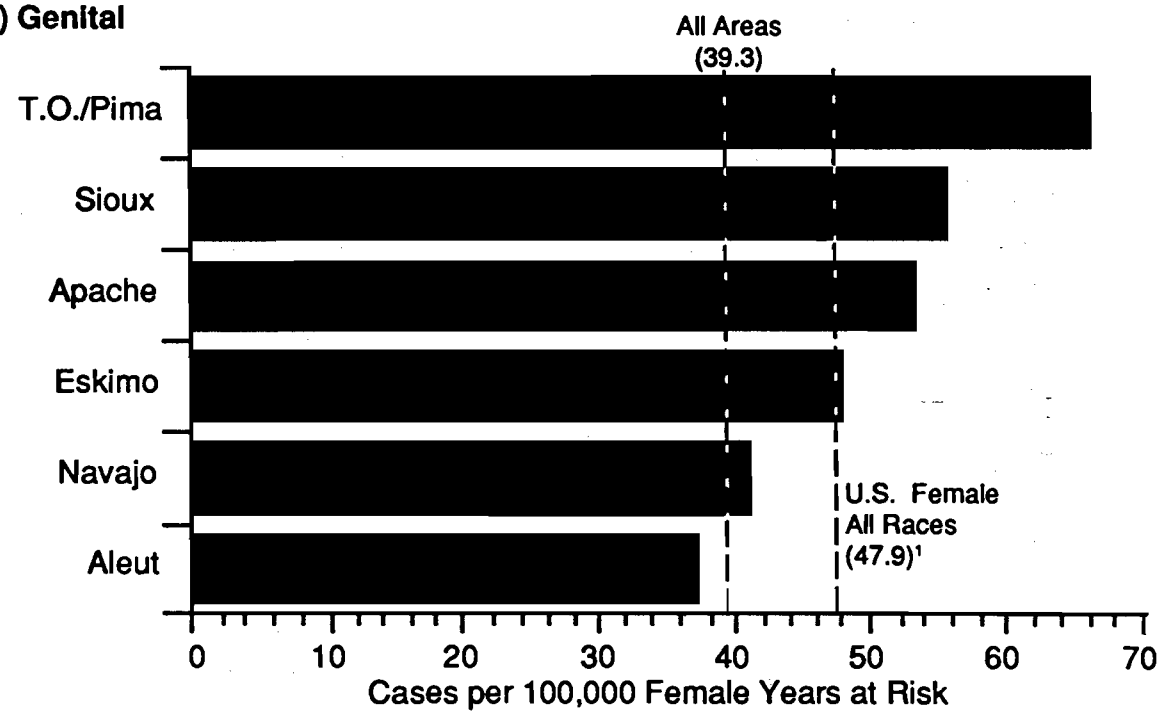
Cervical cancer death rates for all selected IHS Areas exceeded the U.S. All Races rate (3.3) by a factor of two to four times. Portland and Aberdeen were the respective low and high rates Areas for mortality due to cervical cancer (6.0 vs. 14.5) (Figure 3b).

c. Endometrium

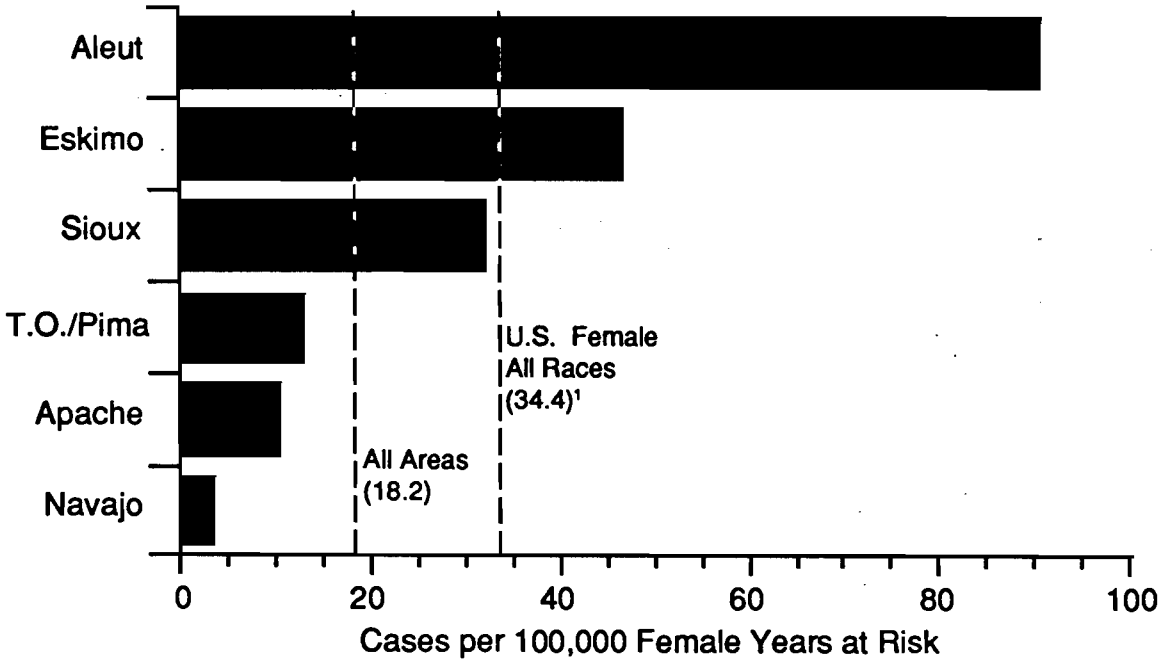
Area-specific mortality rates for endometrial cancer were all well below the national average (Figure 3c).

Figures 2a-2h: Incidence Rates by Tribal Affiliation (Continued)

2e) Genital



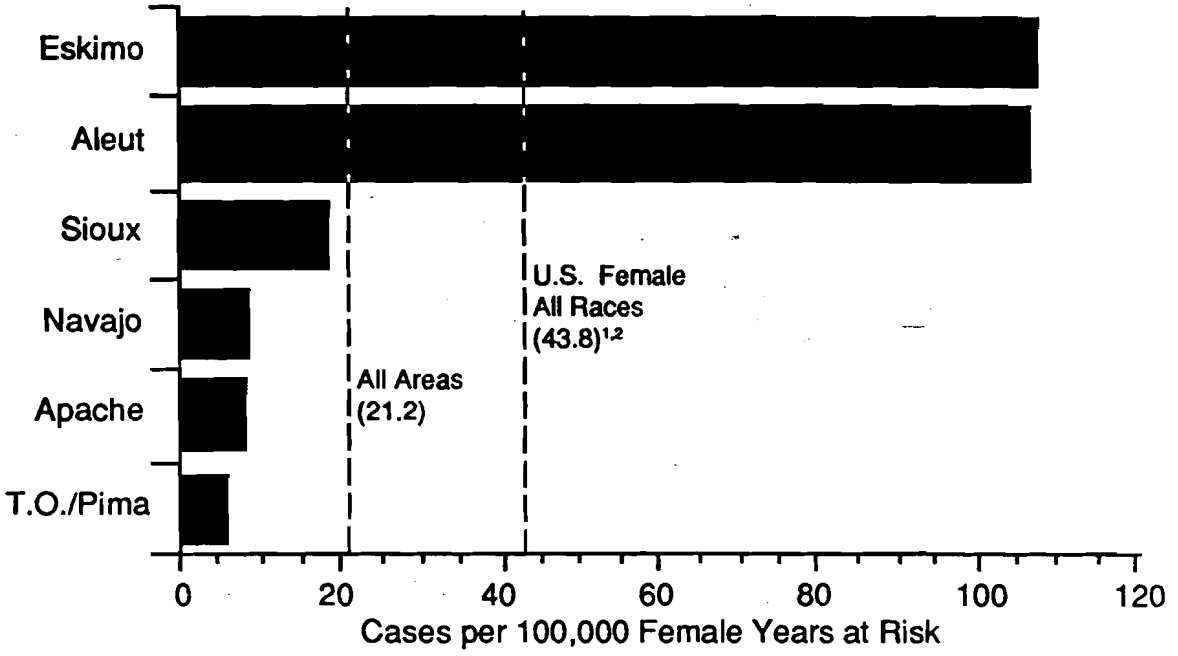
2f) Lung/Bronchus



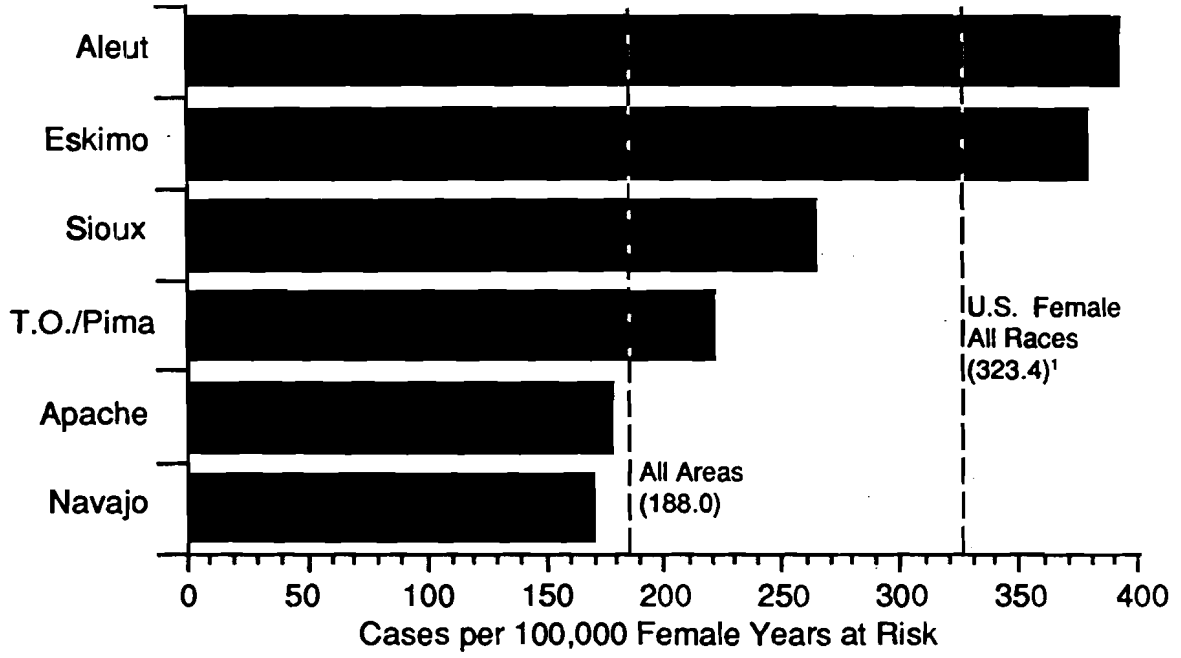
[1]SEER: 1982-1986

Figures 2a-2h: Incidence Rates by Tribal Affiliation (Continued)

2g) Colon/Rectal



2h) All Sites



[1]SEER: 1982-1986
[2]Colon and Rectum Rates were summed for purposes of comparison.

TABLE 9
Number of Selected Cancer Deaths for Selected IHS Areas Among American Indian and Alaska Native Women, American Indian and Alaska Native Mortality Detail Database, 1980-1986.

Area	Breast	Cervical	Endometrial	Ovarian	Genital	Lung Bronchus	Colorectal	All Sites
Aberdeen[1]	24	20	3	11	41	38	15	228
Alaska	18	16	1	8	27	49	29	232
Billings[2]	15	12	1	7	24	36	5	126
Oklahoma[3]	71	35	10	25	77	70	73	528
Portland[4]	17	14	1	25	30	25	12	160
Southwest[5]	70	49	5	24	85	32	29	596
TOTAL	215	146	21	100	284	250	163	1,870

[1]North Dakota, South Dakota
[2]Montana
[3]Oklahoma
[4]Oregon, Washgton
[5]Arizona, Nevada, New Mexico

TABLE 10

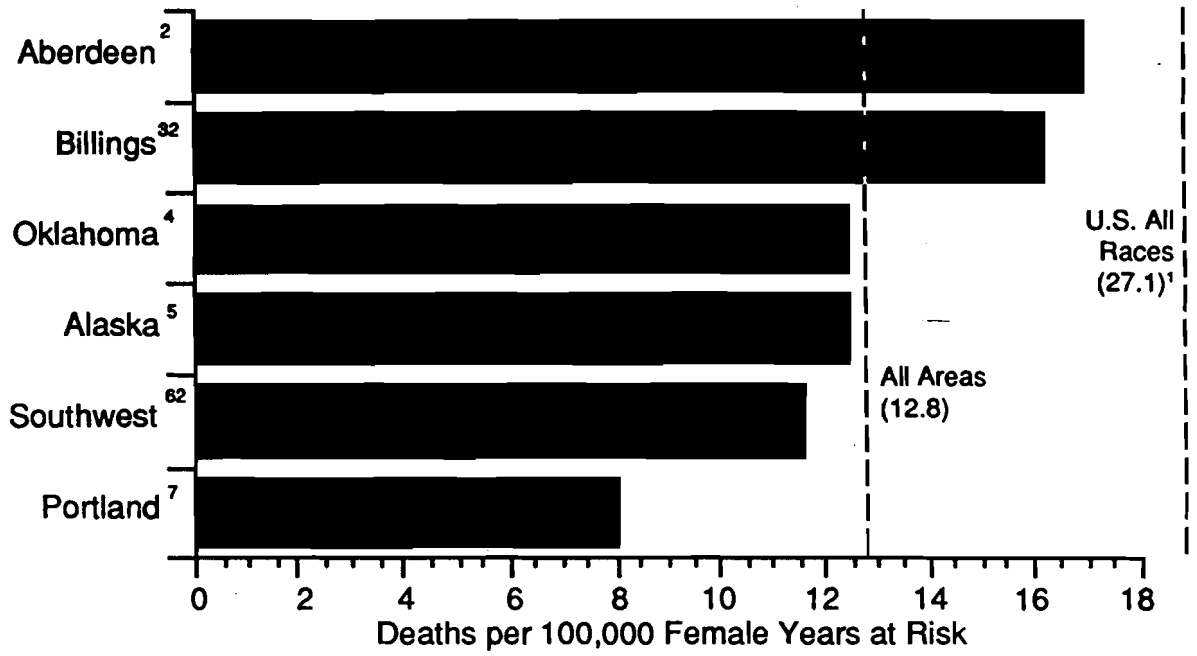
Average Annual Age-Adjusted[1] Cancer Mortality Rates (per 100,000 Female Years at Risk) and 95% Confidence Intervals[2] for Selected Areas Among American Indian and Alaska Native Women Residents of IHS Reservation States, 1980-1986

Area	Breast	Cervical	Endometrial	Ovarian	Genital	Lung Bronchus	Colorectal	All Sites
Aberdeen[3]	17.0 [0,36.3]	14.5 [0,32.0]	2.6 [0.10.4]	8.5 [0,22.1]	31.0 [4.7,55.1]	29.6 [4.1,55.2]	12.4 [0,29,2]	173.6 [11.5,235.7]
Alaska	12.5 [0,28.7]	12.1 [0,29.4]	0.4 [0,2.5]	7.1 [0,21.0]	21.2 [0,44.3]	38.2 [8.2,68.2]	24.4 [0,49.7]	186.8 [118.3,255.3]
Billings[4]	16.3 [0,39.9]	13.2 [0,34.4]	1.3 [0,7.1]	9.4 [0,28.1]	28.6 [0,60.8]	47.2 [5.1,89.3]	7.0 [0,25.9]	158.9 [81.7,236.1]
Oklahoma[5]	12.5 [4.6,20.4]	6.0 [0.6,11.4]	1.8 [0,4.7]	4.5 [0,9.2]	13.4 [5.3,21.7]	12.4 [4.3,20.3]	12.9 [4.9,20.9]	93.2 [71.7,114.7]
Portland[6]	8.1 [0,19.2]	5.8 [0,14.4]	0.6 [0,3.1]	13.7 [0,28.4]	15.0 [0,30.0]	13.7 [0,28.4]	7.3 [0,18.7]	87.7 [49.7,125.7]
Southwest[7]	11.7 [4,19.4]	8.6 [1.8,15.4]	0.9 [0,2.9]	4.0 [0,8.5]	14.9 [5.0,23.8]	6.4 [0.3,12.5]	5.4 [0,10.9]	107.0 [82.8,131.2]
TOTAL	12.8 [8.1,17.6]	7.8 [3.3,9.4]	1.4 [0.3.0]	6.3 [2.9,9.7]	17.2 [11.7,22.8]	16.3 [10.8,21.8]	10.7 [6.2,15.2]	117.0 [102.5,131.7]
U.S. All Races[8]	27.1	3.3	3.8[9]	7.7	17.3[10]	25.2	15.4	138.4

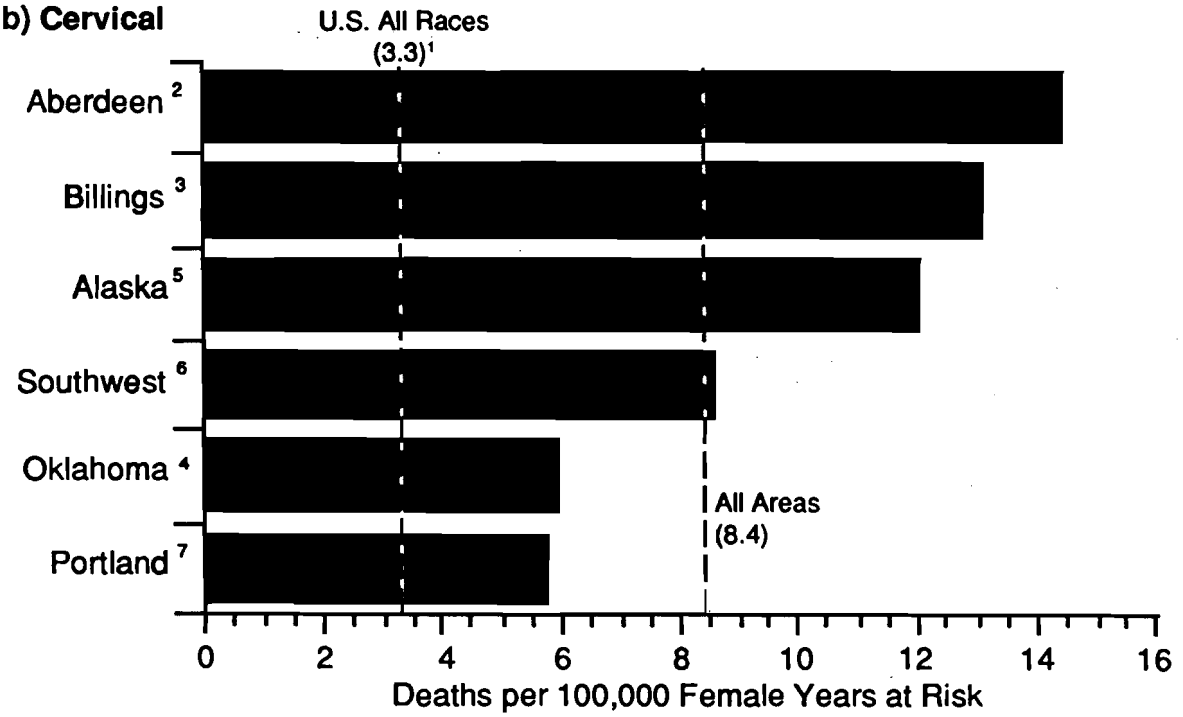
[1]1970 U.S. female population used as standard
[2]The lower bounds of confidence intervals which were negative have been truncated to zero
[3]North Dakota, South Dakota
[4]Montana
[5]Oklahoma
[6]Oregon, Washington
[7]Arizona, Nevada, New Mexico
[8]SEER 1982-1986
[9]SEER reports corpus uteri, NOS
[10]SEER, 1985-1986

Figures 3a-3h: Relative Age-Adjusted Cancer Mort ality Rates for American Indian and Alaska Native Women Who Resided In Selected IHS Areas, 1980-1986

3a) Breast



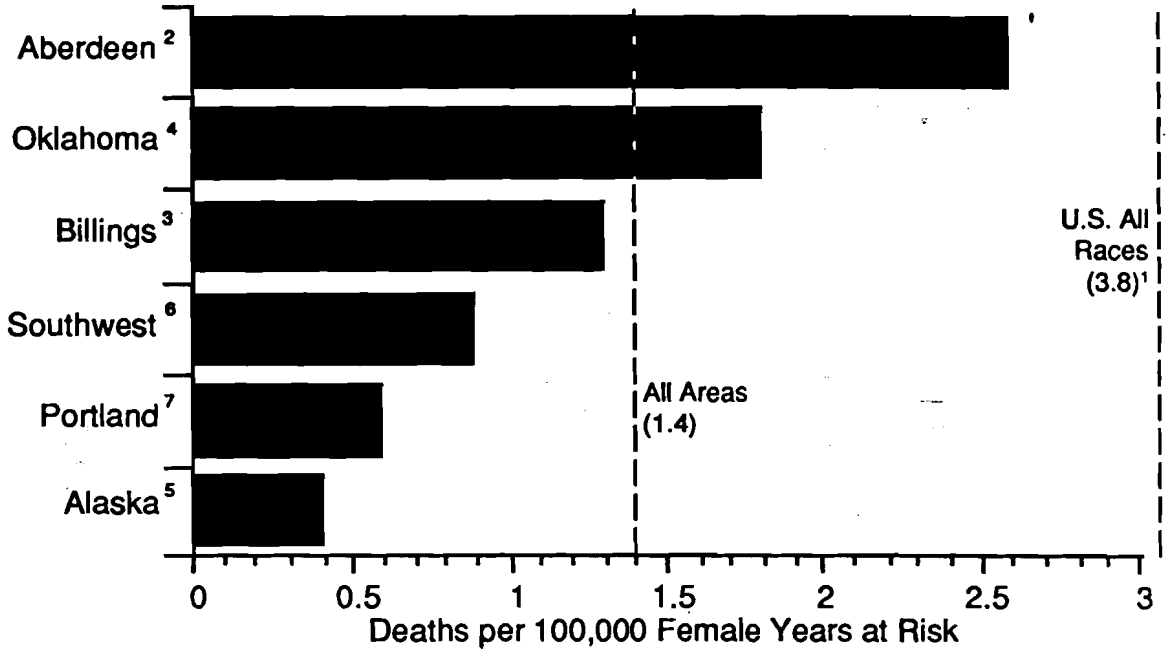
3b) Cervical



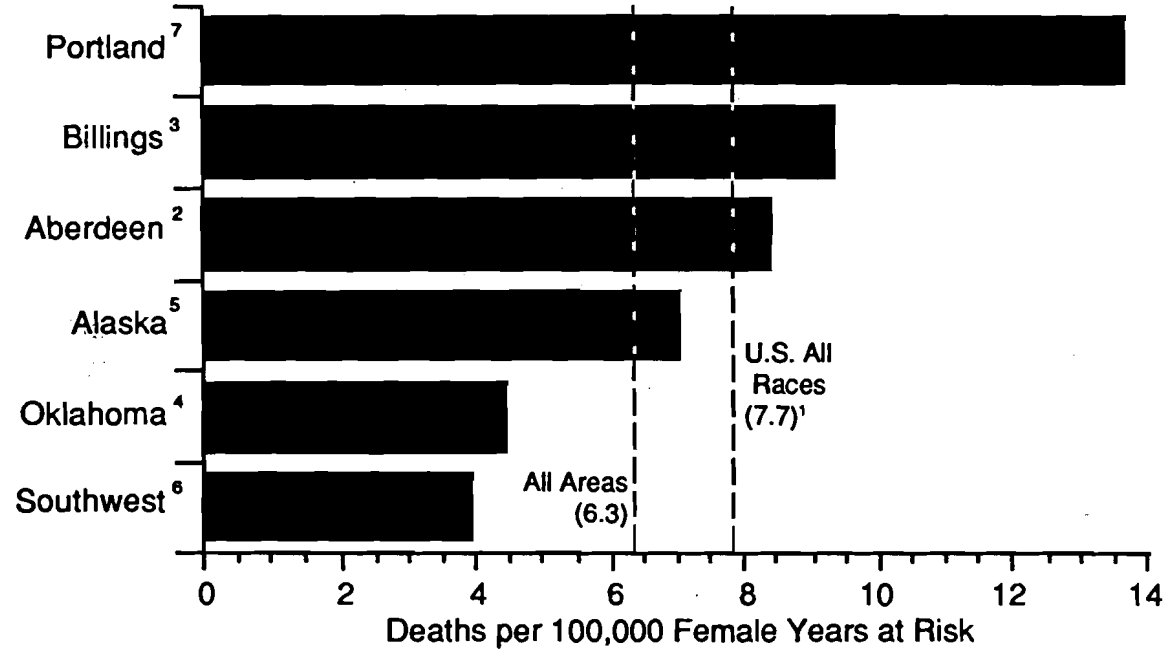
[1]SEER: 1982-1986
[2]North Dakota and South Dakota
[3]Montana
[4]Oklahoma
[5]Alaska
[6]Arizona, Nevada and New Mexico
[7]Oregon and Washington

Figures 3a-3h: Age-Adjusted Cancer Mortality Rates (Continued)

3c) Endometrium



3d) Ovarian



[1]SEER: 1982-1986
[2]North Dakota and South Dakota
[3]Montana
[4]Oklahoma
[5]Alaska
[6]Arizona, Nevada and New Mexico
[7]Oregon and Washington

d. Ovary

The Portland Area mortality rate for ovarian cancer was nearly double the rate for U.S All Races (13.7 vs 7.7, respectively). Death rates from the Billings, Aberdeen and Alaska Areas were comparable to the U.S. rate (Figure 3d).

e. Genital System

AI/AN death rates associated with cancer of the female genital system exceeded the U.S. All Races rate (15.5) for the Aberdeen (31.0), Billings (28.6) and Alaska Areas (21.2). The remaining Areas had rates slightly below the U.S. rate (Figure 3e).

f. Lung/Bronchus

Billings, Alaska and Aberdeen Areas had mortality rates for lung/bronchus cancer which were higher than the U.S. Female All Races rate (47.2, 38.2 and 29.6 vs. 25.2). The Southwest Areas, Oklahoma and Portland had death rates below the national average (Figure 3f).

g. Colorectal

The Alaska Area death rate for colorectal cancer exceeded the U.S. All Races Female rate for colon cancer. There was nearly a five-fold difference between the low and high rate Areas, Southwest and Alaska, respectively (Figure 3g).

h. All Sites

Mortality rates for all cancer sites combined were higher than the U.S. All Races Female rate for the Alaska, Aberdeen and Billings Areas, while Portland, Oklahoma and Southwest Areas had rates below the national average (Figure 3h).

D. Discussion

Several findings in this investigation invite further research. Limitations of the study method will be discussed first and then key findings will be addressed.

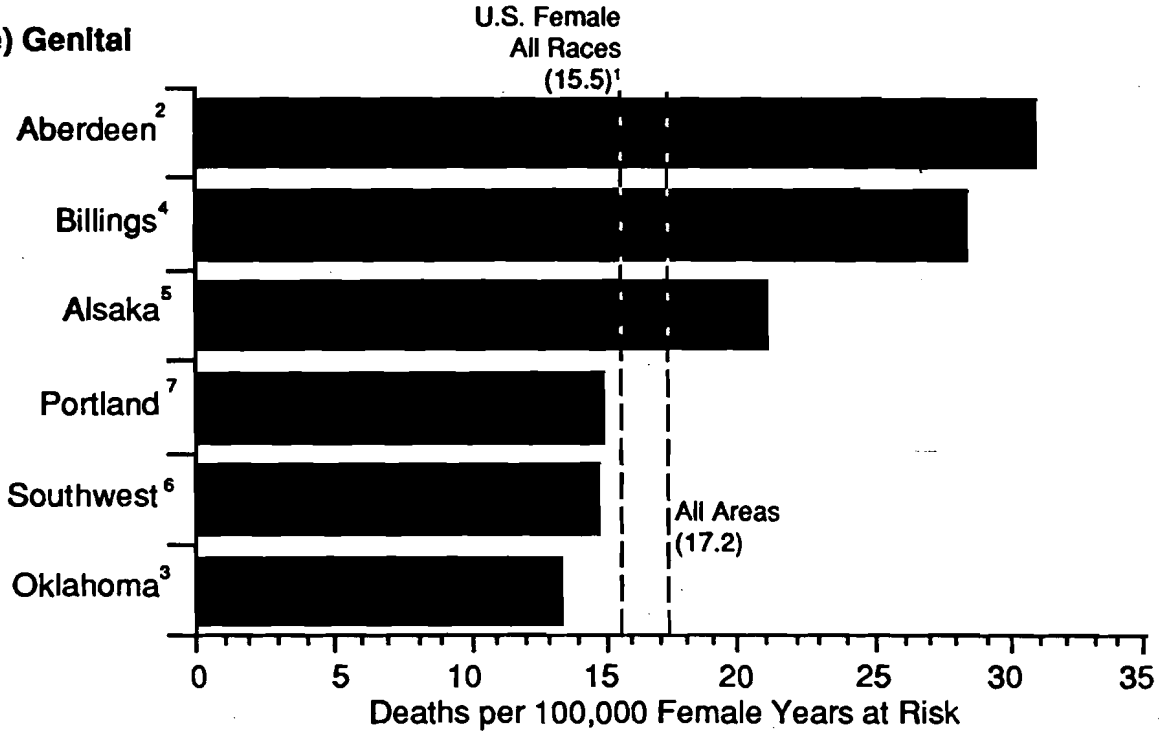
1. Limitations

This study used existing data in order to estimate the incidence of selected cancers among AI/AN women admitted to non-tribal IHS Direct and Contract Hospitals, as well estimate the cancer-related mortality for AI/AN women who resided in a subset of reservation states for which IHS has a responsibility for providing health care services.

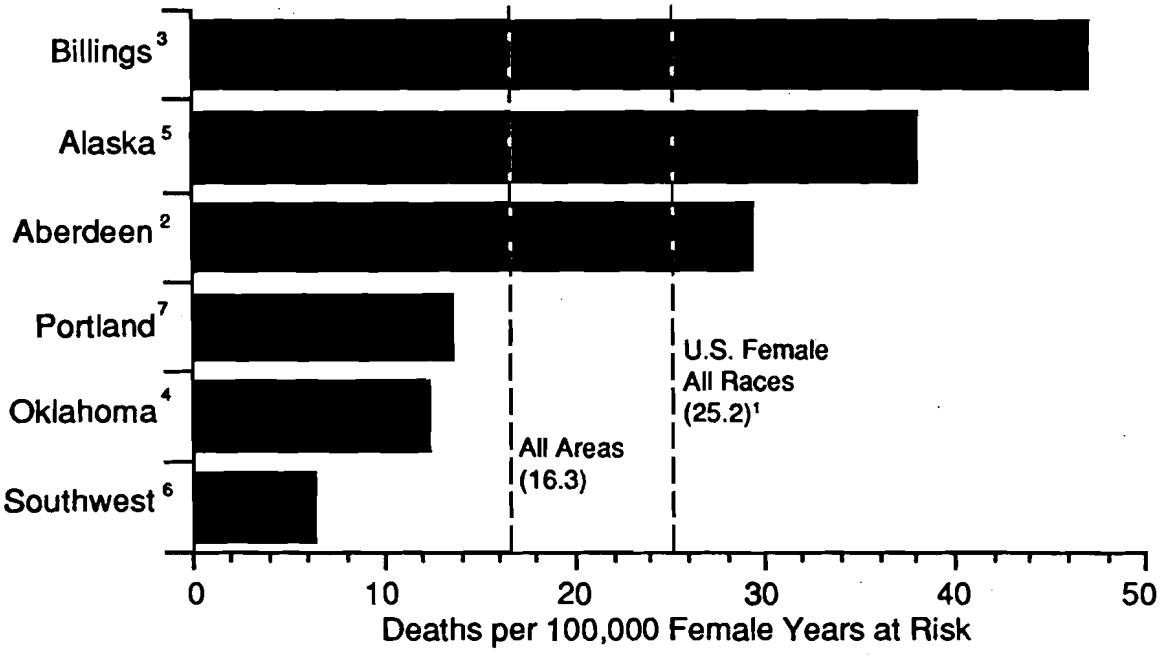
Other investigators have examined hospital discharge data to estimate the incidence of cancer.[11,12,13] In general, they have found inpatient records to be quite accurate measuring the incidence of certain cancer sites and age groups. Unlike the hospital discharge data from which conclusions were drawn in the above mentioned studies, the IHS data base is unique in that admissions can be unduplicated down to an "incident" admission. This important advantage over

Figures 3a-3h: Age-Adjusted Cancer Mortality Rates (Continued)

3e) Genital



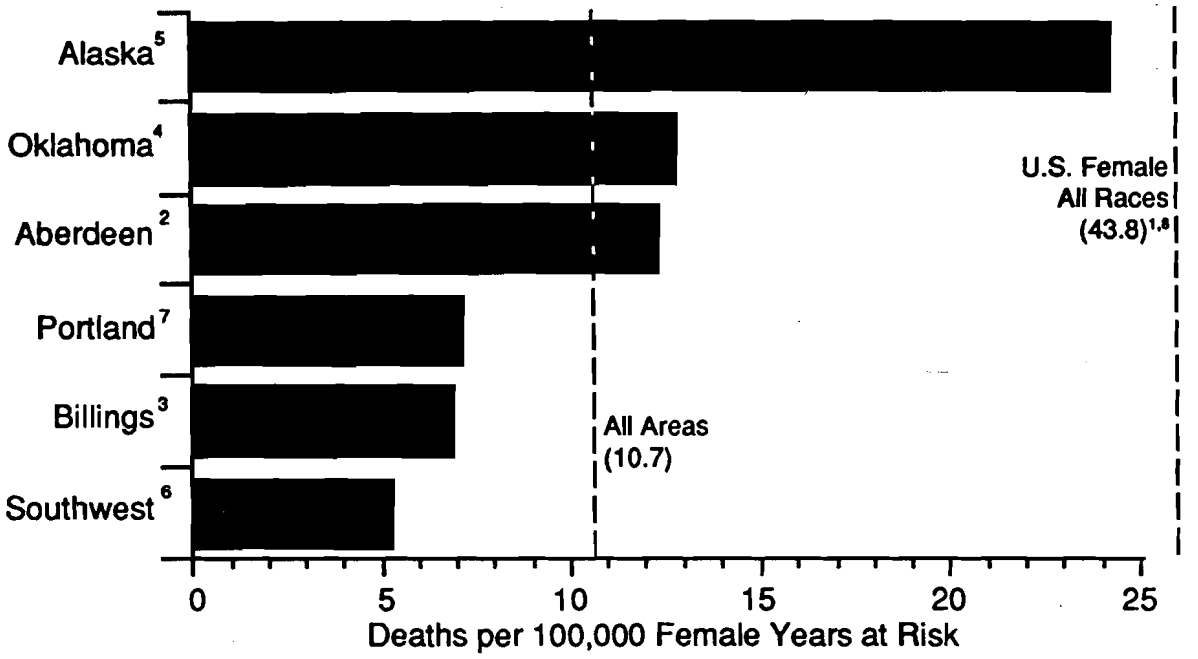
3f) Lung/Bronchus



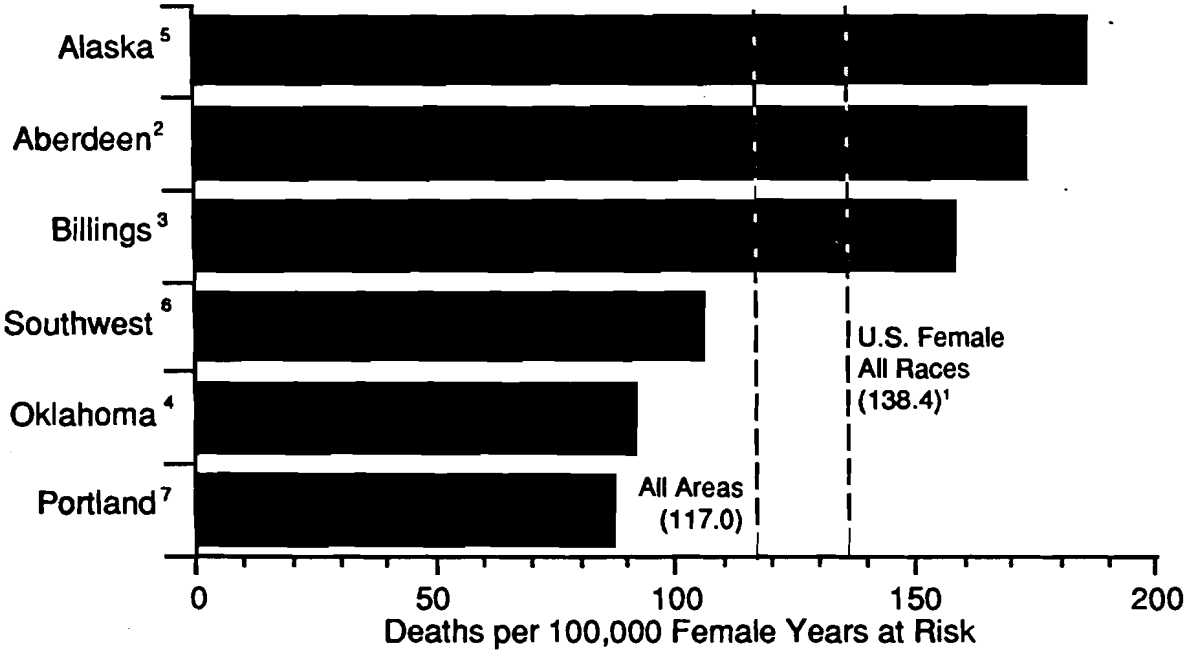
[1]SEER: 1982-1986
[2]North Dakota and South Dakota
[3]Montana
[4]Oklahoma
[5]Alaska
[6]Arizona, Nevada and New Mexico
[7]Oregon and Washington

Figures 3a-3h: Age-Adjusted Cancer Mortality Rates (Continued)

3g) Colon/Rectum



3h) All Sites



[1]SEER: 1982-1986
[2]North Dakota and South Dakota
[3]Montana
[4]Oklahoma
[5]Alaska
[6]Arizona, Nevada and New Mexico
[7]Oregon and Washington
[8]Colon and Rectum rates were summed for purposes of comparison.

other inpatient record systems such as the National Hospital Discharge Survey (NHDS) and the Commission on Professional and Hospital Activities-Profession Activity Study (CPHA-PAS) further bolsters our confidence that the IHS Inpatient Data Base can be valuable in the surveillance of cancer trends among AI/AN who use IHS medical services. However, because hospital discharges may reflect various local factors, including health care policies, diagnostic patterns, treatment modalities and reporting practices, interpretation of rates should be made with these limitations in mind.

The problems associated with using information gleaned from death certificates for epidemiologic study have been documented.[14] A unique problem associated with using existing data for determining the health status of the AI/AN people is the accuracy of racial classification reported on death records. The extent to which misclassication of race underestimates the burden of mortality among the AI/AN people is presently unknown, but is thought to vary from state to state (Personal communication: Steve Helgerson MD, MPH, Senior Epidemiologist for the Billings and Portland IHS Areas).

Since it is not possible to distinguish deaths for AI/AN women based on where they received medical care (ie., IHS vs. non-IHS facilities), mortality rates include all women identified as AI/AN regardless of primary source of medical care. The study method used attempted to control for this situation by calculating Area mortality rates exclusively for states with at least 80% of the total AI/AN population being geographically eligible for medical services provided by the IHS.

Reported rates for incidence and mortality were based upon population estimates derived from the 1980 U.S. Census. Recent review of the IHS Patient Registration System indicated that the Census-based Service Population counts may actually underestimate the populations at risk. Presently, the extent to which these two population counts differ is unknown. Therefore, the rates reported in this study may be inflated to some unknown degree. Further investigation into this issue is critically important to future health status research within the IHS.

Readers need to realize that caution should be exercised in the interpretation of estimated rates and their associated confidence interval. Given that small numbers do come into play in the estimating of some rates (Tables 5,7), the observed variance and standard error of the rate can be relatively large. Therefore, large relative differences between Areas and/or tribes may not be statistically significant.

2. Key Findings

For each of the cancer sites studied the Overall IHS rate was below the rate reported for U.S. All Races. However, marked variations among IHS Areas were observed and for various cancer sites certain IHS Area rates were above the U.S. rate.

The North (high rates) to South (low rates) geographical variation in the occurence of breast cancer are consistent with previous regional studies.[2,3,4,15,16] The overall IHS mortality associated with breast cancer, based on selected Areas, was 12.8 per 100,000 female years at risk. Funk reported a similar rate, 12.1, for the years 1974-1983.[15] Although the Alaska Area had the highest incidence of breast cancer, the Area mortality rate was below the average IHS rate. Unlike Alaska,

the Aberdeen and Billings Areas had both high incidence rates and mortality rates associated with breast cancer.

The IHS rate for invasive cervical cancer is more than double the rate for the U.S. All Races. Other investigations have observed high rates of cervical among Indian women, also.[3,4,17,18] Alaska had the highest incidence with the third highest mortality associated with cervical cancer. Aberdeen Area was ranked third for incidence and had the highest mortality rate for this cancer site.

Although the overall occurence of endometrial cancer in the IHS was one third the national average, the high rates observed for the Tucson and Phoenix Areas were striking. This finding invites further investigation in order to identify risk factors associated endometrial cancer for Indian women living in southern Arizona.

Ovarian cancer occurred less frequently in AI/AN served by the IHS compared to U.S. all races. However, the Portland Area was observed to have the lowest incidence of ovarian cancer but the highest mortality associated with this cancer site.

The marked variation in the distribution of lung and bronchus cancer within the IHS appears to be associated with smoking habits, as evidenced in the rarity of disease among American Indians from the Southwest, where cigarette smoking is relatively uncommon, compared to high incidence of lung and broncus cancer in Indians where the prevalence of smoking is reportedly high (Northern Plains Indians and Alaska Natives).[19]

The Alaska Area women have a strikingly high rate of colorectal cancer relative to both the IHS overall rate and the colon cancer rate for the U.S. All Races. This finding has been reported in other studies, as well.[4,20]

Each IHS Area has an all sites cancer rate considerably below the U.S. All Races Female, with the disturbing exception of the Alaska Area. The Billings, Aberdeen, Nashville and Bemidji Areas had intermediate allsites cancer rates, while Southwest Areas, Oklahoma and Portland Areas had the lowest rates for all cancers combined.

Opportunity exists for IHS and other investigators to repeat studies of this kind in the future to monitor trends in the occurence of cancer among American Indian and Alaska Native people. As future studies focus on "potential explanations" for the findings herein—the "quality" of data and interpretative possibilities may improve.

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IV. PATTERNS OF CARE OF BREAST AND CERVICAL CANCER: PERFORMANCE OF THE HEALTH CARE SYSTEM

A. Introduction

The incidence of cervical cancer is higher among American Indians and Alaska Natives than for all-races U.S. women. As noted in Section III, the age-adjusted rate is 20.1 per 100,000 for Indian women from all IHS Areas, compared to 8.8 for U.S. all-races. In contrast to the pattern of the general U.S. population, some IHS Areas experience a cervical cancer rate either comparable with or slightly greater than that of breast cancer. The incidence of breast cancer, on the other hand, is lower among American Indian and Alaska Native women than among U.S. all-races (32.7 compared to 97.0 per 100,000). In both instances, death is avoidable when the malignancy is discovered early. Early detection, however, is a function of both patient and health care system behavior; and there is evidence that cancer in American Indians of the Southwest is diagnosed at a later stage and associated with worse stage-specific survival than other ethnic groups of the Southwest.[1]

Previous data suggest that screening has not been very successful for either cervical or breast cancer in the IHS population despite the existence of specific quidelines.[2,3] A number of solutions have been proposed including more specially designated women's clinics, education (and exhortation) of providers, non-physician screeners and screening mammography. In order to select wisely among the variety of possible solutions, it is necessary to clearly understand the current impediments to adequate screening.

We have made cervical cancer screening the principal focus of this study, but because the two procedures are so frequently done on the same visit, breast cancer screening has been examined incidentally. The method used was developed in the Indian Health Service to examine the health care system behavior,[4,5,6,7] and has demonstrated its value in identifying remediable deficiencies in performance of the health care system. This approach has been used in this study to examine the performance of the health care system for early detection of cancer of the cervix and breast.

B. Study Site

Approximately 11,471 Tohono O'Odham people live on or near their 2,855,874 acre reservation in rural southern Arizona.[8] The Sells Service Unit of the IHS provides health services to the T.O. as well as other Indian people living in the area. A 37-bed hospital and outpatient department are located in the community of Sells, located 60 miles west of Tucson. The Service Unit also operates two full time ambulatory care centers, one located 30 miles to the northwest of Sells (Santa Rosa Clinic) and the other east of Sells in the suburbs of Tucson (San Xavier).

The study site is more or less typical of a reservation-based program; two of three clinic locations have a women's clinic. A patient may have separate medical records at all three clinics. In practice, however, it is more usual for a patient to obtain the bulk of her care at one location. However, since the hospital is located at Sells, many San Xavier and Santa Rosa users also have active records at Sells. Because San Xavier is located near Tucson, some of the Tucson patients use both the IHS clinic and other local providers.

Care at the three clinic locations is provided five days a week between about 8:00 A.M. and 5:00 P.M. The Sells Hospital has an emergency room. Within these clinic hours, most patients are seen in general, walk-in clinics. However, during the week, half-day clinic sessions are reserved for special types of patients such as chronic disease, well-child, prenatal and "women's" clinics. Sells and San Xavier have pharmacies; medications are dispensed by the provider at Santa Rosa.

Pap smears and clinical breast examinations are done at all three locations, and all specimens are interpreted at the Phoenix Indian Medical Center. Results are returned directly to the clinical facility of origin for inclusion in the patient's record. Patients from all three sites, whose results are abnormal, are usually contacted and referred to Phoenix for colposcopy or followed clinically until a normal Pap result is obtained. At the present time, a clinician at one site would not have access to the date and result of a Pap smear accomplished at one of the other facilities.

Since the early seventies, the Service Unit has been associated with the development of a pioneering automated patient care data system. The current version of this system is called the Patient Care Component (PCC) of the Indian Health Service's Resource and Patient Management System (RPMS). A part of this system is an encounter form that is used both as the record of the patient visit and as the data entry form. The form is structured to make it easy for a provider to order a Pap smear or a breast exam and also to refer a patient to another clinic or provider.

The Service unit has also served as a developmental site for a method of ambulatory care managment, called "industrial strength triage". During the study period this process was in operation for general or walk-in clinic sessions at two of the locations. In order to recognize and respond to a range of patient needs for service, part of the triage process requires review by the nurse-triager of a patient's record at the beginning of the encounter. This includes recognizing and arranging for needed Pap smears on that visit or making a subsequent appointment—often to the "women's clinic". The patient herself is responsible for the actual scheduling of a subsequent appointment.

The Tohono O'Odham users of the Service Unit are primarily reservation residents (80%); other tribal members live in Tucson or in other small communities in the vicinity of the reservation. Forty-six percent of the population (11,471) is under age 20.[8]

C. Methods

This study examined system performance from three perspectives. The first was population-based; screening rates for age-risk groups were calculated. The second perspective examined specific patient-contacts with the health care system (contacts representing opportunities for screening) and computed the probability that a screening examination was done. This perspective also examined the probabilities of recognition of need for screening as well as the probabilities of completed screening. By disaggregating the data by certain characteristics of the patient encounter (e.g. clinic type, provider of service, time of day, etc.) additional information was collected that describes strengths and weaknesses of the system. The third perspective examined the process of care as a sequence of events involving patient contact, recognition of the need for screening, and accomplishment of the screen. Findings from this perspective computed the proportion of patients that failed or passed successfully through each screening step.

The study population was defined as those women who a) were twenty years old or over in 1988, b) were members of the tribe and c) had at least one visit or encounter with the Service Unit in 1986-88. This screening-eligible population numbered 3,637 women and a random sample of 200 women was selected using the automated data system. During the subsequent data analysis, the number of individuals in the age group over 65 years was enhanced in order to more specifically examine system performance for three age groups (20-39, 40-64, and over 64 years). Women were excluded from the sample if they had a hysterectomy, were under treatment for a previous abnormal Pap, or if during chart review there was evidence that they were receiving most of their health care from sources other than the Sells Service Unit. Table 1 shows the number of women sampled and number of women included in the study by age group.

Table 1
Distribution oof Sample

Age Group	Population	Sample Selected	Final Sample
20-39	2066	114	96
40-64	1183	66	42
65+	378	20	46*
Total	3627	200	184

*This number was originally 20 and was enhanced as described in order to examine the care patterns of this age group.

Manual chart review of each separate medical record (up to three) for each woman in the study cohort was completed to assemble a data set that described the women and their contacts with the health care system. As shown by the data collection protocol of Figure 1, specific data elements included demographic information, date and results of last Pap smear and breast exam, the date the next Pap smear and breast exam were due (based on the one year guideline). Additionally, data were collected on each visit made while a Pap smear was due in order to describe the patient and provider contributions to successful screening.

In the analysis both cervical cancer screening (Pap smear) and a clinical breast examination were considered to be due each year for all women in the study cohort. This is consistent with the IHS standard of care, even though the national guidelines suggested by the American Cancer Society (1980) are less stringent for cervical cancer.

D. Results

Table 2 shows the proportion of the study cohort up-to-date for cervical and breast cancer screening as of January 1989. The overall one-year screening rate was 38% for Pap smears and 36% for clinical breast examinations. Three year rates were also calculated for comparison with other studies. The annual screening rates achieved were not impressive and the rates vary inversely with age (and with risk of breast and cervical cancer). The rates for breast examination compare closely with Pap smear rates, presumably because the two are often performed at the same time.

Figure 1

NAME_____ DATE OF BIRTH_____

COMMUNITY _____ HR # _____

DATE OF LAST PAP_____ Results_____ PAP due:_____

DATE OF LAST B.E._____ B.E. Due_____

DATE OF VISIT:										
MO _____										
DATE _____										
YR _____										
LOCATION _____										
CLINIC TYPE _____										
TIME OF VISIT _____										
PROV TYPE _____										
NEED FOR PAP RECOG _____										
PAP ORDERED _____										
PAP DONE _____										
NEED FOR BE RECOG _____										
BE ORDERED _____										
BE DONE _____										
MAMM ORDERED _____										
MAMM DONE _____										
PAP RESULTS _____										
OTHER _____										
WOMEN'S CLINIC APPT _____										

Table 2
Screening Status of Sample as of January 1, 1989

Age Group	Pap Smears (Up-to-date screened in 1988)	Screened in last 3 years
20-39	45% (43/96)	75% (72/96)
40-64	33% (14/42)	52% (22/42)
65+	15% (7/46)	43% (20/46)
Overall*	38%	65%
	Clinical Breast Examinations**	
20-39	40% (39/97)	74% (72/97)
40-64	36% (17/47)	49% (23/47)
65+	17% (8/48)	46% (22/48)
Overall*	36%	64%

*Weighted average based on stratified sample
**The denominator for clinical breast examinations includes women who were excluded from the Pap screening denominator because they had a hysterectomy.

In order to better understand the system factors that contribute to the low screening rates, we first calculated the probability of being screened, given that the patient made a visit when the procedure was due. Thus, visits made when due for screening represent screening opportunities and Table 3 shows the rate at which the system capitalizes on such opportunities. The women in the sample made a total of 678 visits when due for screening. Given a screening opportunity, the youngest age group had a better chance of being screened (17%) than the 35-64 year olds (7%) or the 65+ group (5%). Interestingly, the older age group made the largest number of visits per patient (6.1) when due for a Pap smear, compared to 4.1 and 2.3 for the 40-64 and 20-39 year olds, respectively. Thus, although the older age group offered the largest number of screening opportunities, the probability of being screened on any given opportunity was the lowest of three age groups. The percentage of encounters at which a Pap was done and the percentage at which a breast examination was done are quite similar, again suggesting that both procedures are often done concurrently. For example, during 1989 the women in the sample had a total of 65 Pap smears; on 86% of these visits breast examinations were also done.

Table 3
Probability of Getting a Needed Pap or Breast Exam

Pap			Breast Examinations		
Age Group			Age Group		
20-39	38/222	17%	20-39	32/224	14%
40-64	13/174	7%	40-64	16/197	8%
65+	14/282	5%	65+	15/292	5%

Successful screening requires three steps—contact when due, recognition of need, and doing the screening procedure, a Pap in this instance. Using specific visits as the unit of analysis, each of the three steps were examined separately. Table 4 shows the distribution of contacts (when screening was due) by clinic type and by age group. It is clear that most of these contact opportunities occur in the general clinic (over 50% for all age groups); chronic disease clinics present important opportunities for the 35-64 age group and contact with the pharmacy (presumably for medication refill) represents an important opportunity for the group 65 and over. Women's clinic appears to offer screening opportunities mostly in the youngest age group consistent with the provision of prenatal care in women's clinic. In the older age group women's clinic only offers 3% of the screening opportunities, and would thus appear to play an insignificant role in cancer screening for the older woman.

Table 4
Distribution of Opportunities for Screening by Age Group and Clinic Type

Age Group	General Clinic	Emergency	Pharmacy	Women's Clinics	Chronic Disease	Other*
20-39	55%	12%	5%	14%	4%	10%
Total Encounters 222	(122)	(26)	(12)	(31)	(9)	(22)
40-64	52%	6%	8%	7%	16%	11%
Total Encounters 174	(91)	(10)	(14)	(13)	(27)	(19)
65+	51%	7%	18%	3%	11%	11%
Total Encounters 282	(143)	(20)	(52)	(8)	(30)	(29)

*Opthalmology, optometry, physical therapy and podiatry

Table 5 shows the rate (by clinic type) at which the need for screening was recognized, given a screening opportunity. Recognition of need consisted of either doing the Pap at that visit or indicating that the woman should make an appointment to women's clinic. Women's clinic has an excellent rate of recognition (and completion) for all three age groups, but the contacts occurring at womens' clinic represent less than 10% of all screening opportunities for the two older age groups. Women's clinic represents a higher proportion of encounters for the 20-39 year age group, probably because of the frequency of prenatal visits in this age group. The relatively high rate of recognition from the general clinic for the 20-39 year age group may be due in large part to recognition of pregnancy rather than recognition of need for cancer screening per se. Recognition of need is poor for the 40-64 group and the 65 and over group in general clinics, but is better for these women in the chronic disease clinics. Pharmacy contacts do not often result in recognition of need, however, the fact that need is recognized occasionally suggests that pharmacy visits are a possible point of recognition.

Table 5
Probability of Having Need Recognized,
Given Opportunity for Screening Pap Smears - 1989

	Clinic Type						
Age Group	General Clinic	Emergency	Pharmacy	Women's Clinic	Chronic Disease	Other	Totals (Age)
20-39	48% (59/122)	4% (1/26)	8% (1/12)	74% (23/31)	56% (5/9)	0% (0/22)	40% (89/222)
40-64	27% (25/91)	0% (0/10)	7% (1/14)	100% (12/12)	56% (15/27)	0% (0/19)	20% (53/174)
65+	17% (25/143)	5% (1/20)	2% (1/52)	100% (8/8)	43% (13/30)	0% (0/9)	14% (48/282)
Totals (Clinic)	40% (109/274)	3% (2/56)	4% (3/78)	84% (43/51)	50% (33/66)	0% (0/69)	28% (190/678)

*Includes opthalmology, optometry, physical therapy and podiatry.

Once contact has been made and the need for screening has been recognized, only the performance of the Pap smear remains for successful completion of the screening. This may occur during the visit at which the need was recognized, or the woman may be offered a return appointment or an appointment to women's clinic, the latter being the predominant pattern in the study site. Table 6 shows the rates at which Pap smears are done, given contact and recognition of need for the major clinic types. Clearly, the women's clinic performs best, yet the overall rate at which Pap smears are accomplished, given contact and recognition is only 34%. As noted above, recognition of need at the chronic disease clinic is relatively high, but completion of the procedure is very poor.

Table 6
Probability of Getting Pap Done, Given Recognition of Need

	Clinic Type					
Age Group	General Clinic	Emergency	Chronic Disease	Women's Clinic	Pharmacy	Totals
20-39	22% (13/59)	100% (1/1)	20% (1/5)	100% (23/23)	0% (0/1)	43% (38/89)
40-64	4% (1/25)	0% (0/0)	0% (1/15)	100% (12/12)	0% (0/1)	25% (13/53)
65+	24% (6/25)	0% (0/1)	0% (0/13)	100% (8/8)	0% (0/1)	29% (14/28)
Totals	18% (20/109)	50% (1/2)	3% (1/33)	100% (43/43)	0% (0/3)	34% (65/190)

Having examined the performance of the health care system in achieving patient contact, recognizing the need for screening, and completing the screening procedure, a continuity sequence can be used to examine the impact of this pattern of system performance on the probability that a given woman will be successfully screened. It is useful to examine the flow of patients through the three steps of the process. The results are shown in Table 7 and Figure 2. Clearly the major dropout point is between recognition of need and completion of screening, both as the relative deficiency as well as in absolute numbers. Of those women who dropped out of the process of care (n=119), 42% do so after contact and recognition. These findings reinforce the suggestion that contact with the system and recognition of need are the relative strengths of the system, but completing the Pap smear (often requiring a separate visit to women's clinic) is the relative weakness.

Table 7
Probability of Receiving a Pap

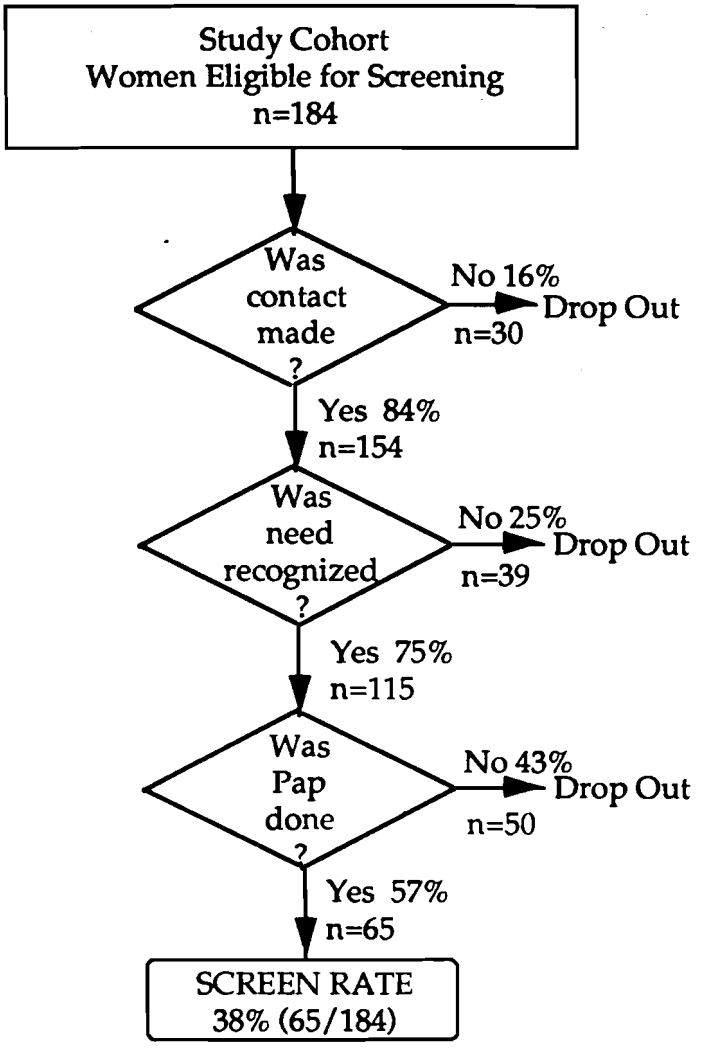
Age Group	Number In Group	% Making Contact	Of Those Who Made Contract % Recognized	Of Those Who Were Recognized % Screened
20-39	96	73% (70/96)	80% (56/70)	68% (38/56)
40-64	42	100% (42/42)	74% (31/42)	42% (13/31)
65+	46	91% (42/46)	50% (28/42)	50% (14/28)
All Ages	184	84%	75%	57%

E. Discussion

A comparison of these population-based screening rates with data from other studies demonstrates similar results. A recent project on the Navajo Area of IHS[2] found that 40% of the women had been screened in the past year, compared to 38% in this study. Data from the National Health Interview Survey in 1987[3] reported 56% having had a Pap in the previous year. This survey also reports that this rate drops to 48% for women with an annual family income of less than $10,000; on the local reservation, 50% of those who could be in the labor force are unemployed and 62% of the individuals who are employed earn less than $5,000 per year.[8] The Navajo study reported that 64% of their subjects had received a Pap in the past three years as compared with 68% in this study. The NHIS, 1987, reported that 88% of women surveyed said they had had a Pap at some time.

Examining the steps in the process of care for cervical and breast cancer screening reveals that a lack of contact is not the reason behind the low screening rates. Eighty-four percent of the sample made contact with the health care system at a time when a Pap was due. Since less than 50% of those who made contact were screened, mounting an outreach effort to bring more women in

FIGURE 2: Probability of Success - Cervical Cancer Screening, Sells Service Unit, 1989



contact will not be productive unless the system can improve its ability to complete a Pap, given that the patient has made a visit.

Recognition of the need for screening was not remarkable. In the youngest age group, this recognition may often have been recognition of pregnancy rather than recognition of need for a Pap smear. In the older age groups, recognition often occurred in the chronic disease clinics (especially diabetic clinic) where the procedure was almost never performed.

Women's clinics are becoming popular in the IHS as a strategy to increase cancer screening. However, these data suggest that separate women's clinics may have only minimal effect on the overall screening rates of a community although they perform well for the women who use them. Unfortunately, only a small proportion of the total population at risk use the women's clinic. The women in this study cohort were referred to women's clinic a total of 125 times, but made only 23 visits in response to the referrals. Table 4 suggests that the cohort of women actually made 52 contacts with women's clinic, the difference being in those women who were self-referred to women's clinic. Thus, women's clinic appears to meet an important need for those women who choose to use it and are self-referred, but the need for a separate return visit provides an additional opportunity for a patient who may be ambivalent about cancer screening to drop out of the process of care. The Sells Service Unit has recently modified the notion of a women's clinic, replacing the separate clinic session with a female provider available during all clinic sessions for cancer screening and other female health promotion services.

Work is currently underway to follow up on several interesting results of this study. In particular, the characteristics of both the patients and the encounters at which screening is successfully accomplished will be compared with the characteristics of patients and encounters at which opportunities for screening were missed. Also a more detailed study of the impact of women's clinic on cancer screening rates in the population will be examined. This work will be reported at a later time.

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V. DEVELOPMENT OF AN INSTRUMENT TO ASSESS CANCER KNOWLEDGE, ATTITUDES, AND SELF-REPORTED BEHAVIORS OF AMERICAN INDIAN AND ALASKA NATIVE WOMEN

A. Introduction

The purpose of this project has been to develop ways to assist Indian health programs to identify some factors that lead to the relatively late diagnosis of cancer of the breast and cervix among American Indian and Alaska Native women. This knowledge will assist these health programs to plan culturally sensitive breast and cervical cancer interventions for Native American women.

B. Description of the Project

Screening for breast and cervical cancer can reduce mortality. Women's perceptions of disease, risk and access as well as their feelings of responsibility for their own health influence their use of screening programs. This project was designed to develop a means of evaluating these perceptions. The information can be used by Indian health programs to design strategies to improve screening rates, particularly among women who are at higher risk for breast or cervical cancer.

Phase I

On September 29th, 1989 the Indian Health Service contracted with Economic Development Systems and MESA Services International to develop a survey instrument that could be used in Native American communities. The contractor was responsible for assembling a bibliography of past major projects that surveyed minority and lower socioeconomic populations regarding breast and cervical cancer prevention. Copies of survey instruments used were obtained.

Using this bibliography and, especially, recent surveys that were funded by the National Cancer Institute for use with minority populations, a draft questionnaire was developed. Items were added that were believed to be of special concern to AI/AN females.

To provide guidance to the project, an advisory panel was assembled by the Indian Health Service. The members of this panel are listed in Appendix B. The group included experts from Universities and other government agencies as well as individuals who provide care to Indian women (some of whom are themselves Indian). At their first meeting in December of 1989, this group reviewed the initial draft instrument, suggested changes and strongly recommended that the contractor spend more time in Indian communities developing the instrument. They specifically suggested that the contractor work with age specific "focus" groups of women on two reservations.

Phase II

Following a pilot test using focus groups with urban Indian women in Salt Lake City, the contractor arranged to work with women in the Tuba City, AZ and Shiprock, NM Service Units as well as at Ft. Duchesne, Utah. The contractor obtained permission from the Area Research and Publication Committees and from the IHS Service Units before contacting the specific tribal Health Advisory Boards.

In these focus group sessions, women had the opportunity to discuss the questions and the language, giving the contractors the opportunity to modify the instrument on the basis of the women's discussions. Since many older Indian women are more comfortable in their own language that they are in English, these groups also afforded the contractors an opportunity to evaluate the difficulties associated with translation. A total of eight groups were completed; fifty-seven women were involved, 31 from Shiprock and 26 from Tuba City.

On the basis of these pilot tests, the contractors reworded questions that contained negatives, reduced the number of responses (on questions that required gradations) from five to three, and eliminated questions about likelihood of cancer. Abstract questions were simplified and questions about the results of screening tests were added.

The revised draft survey instrument was then used in focus group discussions with women from the Northern Ute reservation (Uintah and Ouray), which is located near Roosevelt, Utah. Over a four day period in June, the contractors held discussions with sixteen groups of women; the age categories were 15-24, 25-44, 45-64 and 65+. Between five and seven women in an age group attended a group session. In general, the group discussions for women 65+ were less well attended and required more time due to the need for translation. The questionnaire was revised again on the basis of these experiences and an interim report was prepared by the contractors.

In July of 1990 the advisory panel again met with the IHS Project Officer and the contractors. The results of the field tests at Tuba City, Shiprock and Ft. Duchesne were presented and discussed. The reasons for the focus groups were identified as:

a. Serving as an entree to an Indian community even after the instrument development and testing phases are completed;

b. Acting as an organizing point for training community interviewers; and

c. Creating an opportunity for a local community to add to the core items, concerns specific to the locality.

The panel recommended that focus groups become part of the total protocol for conducting a community survey.

Because of major differences among age groups, the panel recommended that the remainder of the contract be devoted to testing the instrument and the interview process (selecting and training interviewers, detailed instructions for conducting interviews, etc.) in a one-to-one mode. Two additional field sites (different tribes) were suggested; because the initial test sites demonstrated that it is more difficult to interview older women, the panel recommended that the next tests oversample in the older (65+) age group. This oversampling would improve the experience with and, therefore, the instructions for administering the survey to this group of women.

Phase III

The third phase of the project consisted of further field testing. The sites selected were two pueblo communities in northern New Mexico and the Northern Cheyenne reservation, with

headquarters in Lame Deer, Montana. The contractors contacted the appropriate Area research committees in Albuquerque (NM) and Billings (MT). After tribal and Service Unit approval was obtained, interviews were conducted in new Mexico in early September, 1990. Following similar procedures, interviews in Montana were done later that month.

In Albuquerque and at Lame Deer, the contractors located a local coordinator who was familiar with the Indian communities. This person was able to recruit local interviewers, make arrangements for training space and make preliminary preparations to identify potential respondents. In all three communities, the contractors conducted a four hour training for the local female interviewers to:

a. Introduce the interviewers to the purpose of the study,

b. Conduct a focus group session to gain information about the community's perceptions of health care in general and specifically those relating to knowledge, attitudes and beliefs about cancer and cancer screening,

c. Familiarize the interviewers with the instrument and its structure, using role playing to demonstrate how they might respond during an actual interview,

d. Assess the clarity of the questions and attempt to minimize difficulties that might be anticipated in the administration of the questionnaire.

A result of these pilot tests has been the demonstration of the difficulty associated with using tribal rolls as the basis for the selection of a random sample. The contractors reported that tribal lists were available, but these lists could not be used to develop sublists of females with date of birth and current address, items needed to stratify the population by age and then contact them for interviews. They reported that it would be possible to develop such lists, but that this was not possible within the time constraints of the contract. The contractors used cluster sampling, attempting to sample all the local communities. They did not comment on whether the technique, which is used frequently in urban settings, can be used reliably in rural settings to obtain a random sample of the population. In this test setting, they attempted to randomly select equal numbers of respondents for each age group.

The results of these tests were presented to the Advisory Group in November of 1990. The contractor had been asked to assess the clarity of the survey instrument and the acceptance of the questions by the women. This was accomplished by asking the respondent herself if she had any questions following the interview and asking the interviewer to complete a brief assessment of each interview. The contractor also completed an analysis of non-responses which revealed that there were more non-responses among the Cheyenne group than among the Pueblos and among the older women than in the younger. About 35% of the women (both groups) completed the interview in 20 minutes or less.

At the final Advisory meeting, the group recommended that the contractor complete his work by submitting the final set of revised interview questions together with instructions to the interviewer for each question. The Panel reminded the IHS that in order to complete this project, detailed plans for training interviewers must be developed as well as standardized methods for sampling within a community, and entering and analyzing the data.

READ Hello, my name is _____. We are taking a survey for the _____(Tribe/ Indian Organization/Health Corporation). We would like your help to get a better understanding of what women here believe about cancer and cancer screening. Of special interest to women are the cancers of the breast and of the cervix. You were randomly selected as the person in your household to participate in the study. This interview will take about a half-hour to complete. Your answers will be confidential and your name will not be associated with your answers. Your cooperation is completely voluntary. You may refuse to answer any question you choose. We really would appreciate your participation because we need to know what the women here think about these issues. This will help a great deal in planning future health programs for women here.

1. Will you help us? ___
   IF YES, GO TO 2
   IF NO
   Could we reschedule for another time? ___ Yes ___ No
   IF NO, PROBE—DON'T LOSE INFORMANT
   IF YES, RESCHEDULE FOR _____
2. Time interview started _____
3. Time interview ended _____
4. Result of last contact:
   _____Interview completed
   _____Partial interview. Reschedule for: _____
   _____Terminated
   _____Not Home
   _____Refused
5. Respondent ID#_____ Date of:
6. Interviewer:_____ 1st visit _____
7. Interviewer:_____(If required) 2nd visit _____
8. Interviewer:_____(If required) 3rd visit _____

EDITOR: TEAR OFF INFORMATION BELOW

. . . . . .

RESPONDENT'S NAME:_____

I.D. #_____

ADDRESS:_____

1. Overall, would you say that your health now is:
   _____Good
   _____Fair
   _____Poor

2. I am going to read a list of health problems. In your opinion, which ones would you say are the worst problems here?
   _____Heart Disease
   _____Stroke
   _____High Blood Pressure
   _____Diabetes
   _____Violence
   _____Alcohol or Drug Abuse
   _____Or Something Else?
   specify_____
   _____Don't Know

3. Sometimes we learn about health problems like cancer from our relatives or friends. Has your mother or any of your sisters, or any other female relative ever been told she had cancer?
   _____Yes
   _____No
   _____Don't Know
   _____No Answer

3a. Who was it?
   _____Mother
   _____Sister
   _____Other, specify

3b What kind(s)? _____

4. At what age is a woman more likely to get breast cancer?_____

5. At what age is a woman more likely to get cervical cancer?_____

6. Have you been to a clinic or health practitioner in the last year?
   _____Yes
   _____No

6a. What for?_____

7. Thinking over the past year, was there anytime when you needed medical care or advice, but you did not get it?
   _____Yes
   _____No
   _____Don't Know
   _____No Answer

7a. If yes, what was that?
   _____Fear that it would result in something she didn't want to hear
   _____Fear that it would result in something she didn't want to do (such as getting surgery, shots, going into a hospital)
   _____Too busy with other things
   _____Care was not available when needed
   _____Costs too much to get there
   _____Didn't know where to go
   _____Hours not convenient

_____Have been treated rudely in the past
_____Waiting times too long
_____Don't know
_____Other (specify)_____

8. If you wanted to get a check-up or physical examination from a health professional, how difficult or easy would it be for you to get one?
___Very Difficult
___Somewhat Difficult
___Easy
___Don't Know
___No Answer

8a. Why was it difficult for you?

9. Now I'm going to read you a list of conditions. Please tell me if you would personally go to a health practitioner if you had:

a. No appetite for 2 weeks.
___Yes
___Not Sure
___No
___No Response

b. Indigestion or upset stomach for 2 weeks.
___Yes
___Not Sure
___No
___No Response

c. Change in bowel or bladder habits.
___Yes
___Not Sure
___No
___No Response

d. Urine or stools becoming darker.
___Yes
___Not Sure
___No
___No Response

e. Bleeding or discharge.
___Yes
___Not Sure
___No
___No Response

f. Unusually tired or fatigued.
___Yes
___Not Sure
___No
___No Response

g. Coughing up blood.
___Yes
___Not Sure
___No
___No Response

h. Cough or hoarseness for 2 weeks.
___Yes
___Not Sure
___No
___No Response

i. Shortness of breath.
___Yes
___Not Sure
___No
___No Response

j. Chest pains.
___Yes
___Not Sure
___No
___No Response

k. Difficulty in swallowing for 2 weeks.
___Yes
___Not Sure
___No
___No Response

l. A sore that does not heal.
___Yes
___Not Sure
___No
___No Response

m. Thickening or a small lump in the breast.
___Yes
___Not Sure
___No
___No Response

p. White spots in the mouth.
___Yes
___Not Sure
___No
___No Response

q. Changes on skin, rashes, blemishes, blotches.
___Yes
___Not Sure
___No
___No Response

r. Jaundice or yellow skin.
___Yes
___Not Sure
___No
___No Response

10. Now I am going to read a list of statements about health examinations, cancer, and procedures to find cancer early. For each, please tell me if you agree or disagree.

a. Having a general physical checkup once a year is worth the time and effort.
___Agree
___Not Sure/No Opinion
___Disagree
___No Response

b. It is important that people participate in health screening programs such as blood pressure checks.
___Agree
___Not Sure/No Opinion
___Disagree
___No Response

c. Today it seems that just about anything can cause cancer.
___Agree
___Not Sure/No Opinion
___Disagree
___No Response

d. It is important that every woman examine her own breasts for any kind of change.
___Agree
___Not Sure/No Opinion
___Disagree
___No Response

e. If breast cancer is found and treated early, it can be cured.
___Agree
___Not Sure/No Opinion
___Disagree
___No Response

f. If a woman has a lump in her breast, it might be cancer.
___Agree
___Not Sure/No Opinion
___Disagree
___No Response

g. It is important that every woman have a mammogram regularly.
___Agree
___Not Sure/No Opinion
___Disagree
___No Response

h. If cervical cancer if found and treated early, it can be cured.
___Agree
___Not Sure/No Opinion
___Disagree
___No Response

i. It is important for a woman to see a health care practitioner for any unusual discharge or bleeding from the vagina.
___Agree
___Not Sure/No Opinion
___Disagree
___No Response

j. It is important that every woman have a pap test regularly.
___Agree
___Not Sure/No Opinion
___Disagree
___No Response

BREAST PHYSICAL EXAM

11. Now I'm going to ask you some questions about breast physical exams by a doctor, nurse, or other health care practitioner. Have you heard about breast physical exams?
_____Yes
_____No
_____Don't Know
_____No Answer

12. Would you describe a breast physical exam? (Check if description is:)
_____Complete
_____Partial
_____Don't Know
_____No Answer

13. Have you ever had a breast physical exam?
___Yes
___No
___Don't Know
___No Answer

14. How many times in the last 24 months (2 years) have you had a breast physical exam?
_____Number
_____Don't Know
_____No Answer

15. As near as you can remember, what was the month and year of your most recent breast physical exam?
_____Month
_____Year

16. Where did you have it done?_____

17. Was any problem found?
_____Yes
_____No
_____Don't Know
_____No Answer

18. Do you plan to have a breast physical exam in the next 2 years?
_____Yes
_____No
_____Don't Know
_____No Answer

19. Do you know anybody else who has had a breast physical exam?
_____Yes
_____No

20. Who was it?_____
(What is her relationship to the respondent?)

21. What was her experience with the exam?
_____Positive
_____Neutral
_____Negative

22. In the last 12 months where have you read or heard about breast physical exams?
_____I have not read about or heard about breast physical exams.
_____IHS Clinic
_____Television
_____Radio
_____Local Newspaper _____
name
_____School
_____Other (specify)_____
_____No Answer

23. Would you prefer to have a male or female health care practitioner perform the breast physical exam?
___No Preference
___Prefer Male
___Prefer Female
___Don't Know
___No Answer

24. Would you personally refuse a breast physical examination if only male health practitioners were available to do it?
___Yes
___No
___Don't Know
___No Answer

25. Do you think your husband or partner would object to your getting a breast exam by a male doctor?
___Yes
___No
___Don't Know
___No Answer

26. About how often do you think a healthy woman your age should have a breast exam by a health practitioner?
_____At least once a year
_____Every 1-2 years
_____Once every 2-3 years
_____Once every 4-5 years
_____Less than once every 5 yrs.
_____Only when (or whenever) there's a problem
_____Only when she is pregnant
_____Only when a doctor/nurse recommends it
_____Don't Know
_____No Answer
_____Other (specify)_____

MAMMOGRAPHY

27. Now I'm going to ask you some questions about mammograms. Have you heard about mammograms?
___Yes
___Not Sure/Don't Know
___No
___No Answer

28. Would you describe a mammogram? (Is description:)
___Complete
___Partial
___Don't Know
___No Answer

29. Was it a screening?
___Yes
___No
___Don't Know
___No Answer

30. How many times in the last 24 months (2 years) have you had a mammogram?
___Number
___Don't Know
___No Answer

31. As near as you can remember what was the month and year of your most recent mammogram?
___Month
___Year

32. Where did you have it done?
_____

33. Was any problem found?
___Yes
___No
___Don't Know
___No Answer

34. Do you plan to have a mammogram in the next 2 years?
___Yes
___No
___Don't Know
___No Answer

35. Do you know anybody else who has had a mammogram?
___Yes
___No

36. Who was it?_____
(What is their relationship to person)

37. What was their experience?
_____Positive
_____Neutral
_____Negative

38. In the last 12 months where have you read about or heard about mammograms?
___I have not read about or heard about mammograms.
___IHS Clinic
___Television
___Radio
___Local Newspaper_____
name
___School
___Other (specify)_____
___No Answer

39. Would you prefer to have a male or female health care practitioner perform the mammogram or do you have no preference?
___No Preference
___Prefer Male
___Prefer Female
___Don't Know
___No Answer

40. Would you personally refuse a mammogram if only male health practitioners were available to do it?
___Yes
___No
___Don't Know
___No Answer

41. Do you think your husband or partner would object to your getting a mammogram by a male practitioner?
_____Yes
_____No
_____Don't Know
_____No Answer

42. About how often do you think a healthy woman your age should have a mammogram done?
___Every year
___Every 1-2 years
___Every 3 years
___Every 4 years
___More than 5 years

PAP

43. Now, I'm going to ask some questions about Pap smears or Pap tests. Have you heard about a Pap smear or Pap test?
___Yes
___No
___Don't Know
___No Answer

44. Would you describe how Pap tests are done?
___Complete
___Partial
___Don't Know
___No Answer

45. Have you ever had a pelvic examination?
___Yes
___No
___Don't Know
___No Answer

46. Have you ever had a Pap test?
___Yes
___No
___Don't Know
___No Answer

47. As near as you can remember what was the month and year of your most recent Pap test?
_____Month
_____Year

48. Was any problem found on the exam?
___Yes
___No
___Don't Know
___No Answer

49. Where did you have it done?_____

50. Do you plan to have a Pap test in the next 2 years?
___Yes
___No
___Don't Know
___No Answer

51. Do you know anybody else who has had a Pap test?
___Yes
___No

52. Who was it?_____
(what is their relationship to the person)

53. What was their experience with the Pap test?
___Positive
___Neutral
___Negative

54. In the last 12 months where have you read about or heard about Pap tests?
___I have not read about or heard about Pap tests.
___IHS Clinic
___Television
___Radi
___Local Newspaper_____
name
___Other (specify)_____
___No Answer

55. Would you prefer to have a male or female health care practitioner for a pelvic examination?
___No Preference
___Prefer Male
___Prefer Female
___Don't Know
___No Answer

56. Would you personally refuse a Pap test if only male health practitioners were available to do it?
___Yes
___No
___Don't Know
___No Answer

57. Do you think your husband or partner would object to you getting a pelvic examination by a male practitioner?
___Yes
___No
___Don't Know
___No Answer
___Not Applicable

58. About how often do you think a healthy woman your age should have a Pap test done?

BREAST SELF-EXAMINATION

59. Now I'm going to ask you some questions about breast self-examination. Have you heard about breast self-exams?
___Yes
___No
___Don't Know
___No Answer

60. Would you describe a breast self-examination?
___Complete
___Partial
___Don't Know
___No Answer

61. Do you examine your breasts?
___Yes
___No
___Don't Know
___No Answer

62. How many times in the last 12 months have you examined your breasts?
___More than once a month
___Once a month
___Not every month but several times a year
___At least once a year
___Less than once a year
___Never

63. When was the last time you examined your breasts?
___Less than 6 months ago
___6 months to 1 year ago
___1-2 years ago
___3-5 years ago
___More than 5 years ago
___Don't Know

64. Have you ever noticed anything wrong in your breast? Such as pain, a lump, or maybe something like a discharge?
_____Yes
_____No

64a If yes, did you go to a health care practitioner about it?

___If Yes, what happened?
_____
_____
_____

___If No, why not?
_____
_____
_____

65. Do you plan to self-examine you breasts in the future?
___Yes
___No
___Don't Know
___No Answer

66. Do you know anyone who self-examines her breasts?
___Yes
___No

67. Who is this?_____
(How is this person related?)

68. What is their experience with breast self-examination?
___Positive
___Neutral
___Negative

69. In the last 12 months, where have you heard about or read about breast self-examination?
___Have not read or heard about BSE.
___IHS Clinic
___Television
___Radio
___Local Newspaper_____
name
___School
___Other (specify)_____
___No Answer

70. About how often do you think a healthy woman your age should self-examine her breasts?
___Once every month if over 20 years of age
___At least once a year
___Once every 2-3 years
___Once every 4-5 years
___Less than once every 5 years
___Only when there is a problem
___Only when she is pregnant
___Only when recommended by doctor or nurse
___Don't know
___No Answer
___Other (specify)_____

GENERAL INFORMATION

Now, we are on the last section of the questionnaire. Since there may be a relationship between a woman's opinions about cancer and the number of children and pregnancies she has had, I need to ask just a few questions about these issues. Of course, all this will be kept strictly confidential. You do not have to answer any of these questions if you do not feel comfortable answering them.

71. First, what is the year of your birth?_____

72. Do you have any children?
___Yes
___No
___No Response

If Yes,
72a._____How many?

72b._____How old were you when your last child was born?

72c._____How many times have you been pregnant?

72d._____How old were you the first time you became pregnant?

73. Are you working outside your home at this time?
_____Yes
_____No

73a. If Yes,

_____Full time
_____Part time? If part time, _____how many hours per week?

74. Are you responsible for the care of any pre-school age children?
___Yes
___No

74a. If Yes,
_____Number

74b. _____How often daily:

___3-4 days/week
___1-2 days/week

75. What was the highest grade in school that you completed?_____

76. Do you have health care insurance?
___Yes
___No

If Yes,

76a. Does it cover mammograms and Pap tests:
___Yes
___No
___Don't Know
___No Answer

76b. What type of health insurance?
_____Medicare
_____Medicaid
_____Other (specify)_____

77. Describe all your tribal affiliations:
_____
_____

78. That's the end of our questionnaire. That took about_____minutes (hrs). Thank you for your help.

79. Were there any questions that were not clear to you?
_____Yes
_____No

If Yes,

79a. Which ones?

Question #	Reasons
_____	_____
_____	_____
_____	_____

INTERVIEWER (FEEDBACK) INFORMATION

1. Place of interview:
_____Home
_____Other (specify)

2. Was there anyone else there that helped interpret or explain questions?
_____Yes
_____No

If Yes,
2a. Who (specify, relationship, no names)
_____

2b. Did they help respondent with the answers?
___Yes
___No

2c. Why did respondent need help?
_____

3. In addition to questions in 79a, were there any others that appeared to be difficult for this respondents to understand?

   List question # and reason:
   _____
   _____

4. Was the respondent impatient with the interview or in a hurry to get it over?
   ___Yes
   ___Not Sure
   ___No

5. How embarrassed or uncomfortable was the respondent during the interview?
   ___Very
   ___Slightly
   ___Not At All

6. Do you think that the woman accepted the questions as important ones to answer?
   ___Yes
   ___Not Sure
   ___No

7. Anything else noteworthy about this interview?
   ___Yes
   ___No

   If Yes, check all that apply:
   _____Wanted to chat
   _____Offered (non-health) information about self
   _____Offered information about health
   _____Offered information about cancer (specify)

8. Do you personally know this respondent?
   ___Yes
   ___No

   If Yes, is she a
   ___Relative
   ___Friend
   ___Neighbor
   ___Other (specify)_____

9. Check incorrect information given by the respondent about the following?
   ___Breast physical exam
   ___Mammography
   ___Pap
   ___Breast self-exam

ATTACHMENT B
Knowledge, Attitudes and Behavior
of American Indian and Alaskan Native Women
Toward Prevention and Treatment of Cancer of the Breast and Cervix

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VI. KNOWLEDGE, ATTITUDES, AND PERCEPTIONS OF IHS PROVIDERS REGARDING CANCER PREVENTION AND CONTROL

A. Introduction

As part of the general concern regarding the relatively poor survival rates for American Indian and Alaska Native (AI/AN) women diagnosed with breast or cervical cancer, the Indian Health Service (IHS) Office of Health Program Research & Development (OHPRD) in Tucson, with funding support from the IHS Office of Planning, Evaluation & Legislation (OPEL) and from the National Cancer Institute (NCI) engaged in a coordinated set of research projects. These several projects are designed to accomplish multiple broad goals:

...to review and refine information on morbidity and mortality rates for breast and cervical cancer among AI/AN women in selected locations, using multiple data sources,
...to retrospectively review the clinical system's diagnosis and treatment of actual cases in an effort to clarify practices and identify possible missed opportunities for early detection, and
...to identify those beliefs or attitudes of providers and patients which might alter the opportunities for early detection of breast and/or cervical cancer.

The following is a description of that component project dealing only with the knowledge, attitudes and practices (KAP) of IHS providers.

B. Methodology

Early in the development of this project, the principal investigator assembled several OHPRD staff members involved in the various component studies of this cancer research in order to discuss and clarify fundamental approaches to the project. It was through this process that an understanding was reached on the basic format for the survey.

It was agreed that concurrent research activities on the various component studies would benefit most from an initial "broad brush" survey of attitudes which could later become more focused on identified issues in subsequent follow-up iterations of the survey. This anticipates the possibility, or probability, of a phasic approach to the project,...that an initial survey may likely identify questions which we will want to pursue in more detail through additional study.

Given the "broad brush" aspect of the initial survey, it was decided to opt for the use of a fairly brief questionnaire for the data collection instrument, as opposed to the use of telephone interviews or in-person inquiries with a number of providers. This option probably provides us with input from the greatest number of respondents and can be done quite economically,... though it does sacrifice some detail and clarity of response by obviating the opportunity to immediately pursue any response in a conversational mode or to "read" the emotional tone of the responder. There are offsetting advantages and disadvantages involved in almost every aspect of the survey design. An additional advantage of the questionnaire is that it allows us to assure the respondent's anonymity, thus gaining a theoretical degree of candor in their responses.

However, granting anonymity to the respondent also eliminates the possibility of doing any detailed comparison between that respondent's stated beliefs and practices, and their actual

clinical performance. The possibility of utilizing a methodology for matching individual performance with knowledge and beliefs is not ruled out for subsequent phases of the study, but was not built into the first phase.

Decisions regarding the scope of the provider survey relate to both the types of providers who would be surveyed and the geographic area to be covered. Since the research question concerns everything from teaching breast self-examination and chemotherapy to setting up patients for pelvic exams and pap smears,...activities which involve education, community outreach, outpatient and inpatient operations, we felt it important that the initial "broad brush" survey be inclusive of a full range of provider types. Thus, distribution of questionnaires would go to physicians, non-physician primary care providers (NPPCPs), RNs in both the inpatient and outpatient clinical setting, and community health providers in a non-clinic mode. Likewise, in being inclusive, we elected to restrict the geographic area for the survey in order to be dealing with a manageable number of respondents. It was originally intended to distribute the initial questionnaire to 3 IHS Areas - Phoenix, Navajo and Aberdeen. However, serious delays and difficulties were encountered in getting a reliable listing of current provider personnel from the Aberdeen Area, so the final mailing was limited to 743 providers in the Phoenix and Navajo Areas. This compromises our opportunity to compare provider perceptions in the northern tier with those working on the southwestern reservations

Since this study is being performed under the general rubric of a provider KAP survey, it is important to understand that the initial "broad brush" phase was not planned or conducted with a full spectrum of attention devoted to knowledge, attitudes and practices. As has been mentioned, the anonymity of the respondents does not permit the matching of clinical practices to stated attitudes, so the initial questionnaire was intentionally designed with minimal inquiry about the actual practices of the respondent. Also, the decision was made to provide the respondent with a set of generally accepted screening standards for comment, rather than to "test" the respondent's knowledge of screening criteria or the pathophysiology of breast and cervical cancer. Thus, the first questionnaire is essentially an attitudinal survey which attempts to achieve the following objectives:

...to assess provider attitudes toward prevention, generally, and how they see their role in the screening function, in particular

...to assess provider perceptions of an ideal or improved approach to cancer screening and some of the more obvious obstacles to achieving those improvements

...to identify any differential between attitudes toward the early detection of breast cancer, and the early detection of cervical cancer

...to utilize a format which enables us to identify group variations in perception based on age, amount or type of training, gender or clinical experience of the respondents.

C. Development of the Questionnaire

A literature search was performed, seeking any study which had raised similar questions regarding provider KAP for the prevention of illness, barriers to implementation of prevention

practices and, in particular, any which dealt with attitudes toward screening for breast or cervical cancer. Quite a few articles were identified (see bibliography) and summaries or reprints of most of them were obtained. Generally, they were helpful in suggesting concepts which we might use, but lacking in the sort of specificity that might have rendered them useful in making comparisons between populations or in providing an easy format for use in our own questionnaire.

The provider group queried in virtually all of the studies we identified consisted of **physicians only**. The subject of the study questions in those articles ranged from nutrition counseling and smoking cessation to periodic health examinations. However, the majority of reports dealt with physician attitudes and activities as they related to health promotion and disease prevention in the primary care setting. Several of the studies dealt, at least partially, with screening for breast and/or cervical cancer. These were predominantly of three types, with varying benefits and drawbacks:

(a) Telephone interviews of approximately 25 minutes duration, comparing attitudes and beliefs with self-reported practices. This method provides better penetration of the selected population (one study reported only 14 refusals of 134 physicians called), but at a somewhat higher cost than a mailed solicitation,...and the subjective responses are more likely to display a normative bias, especially regarding the self-reported practices.

(b) Chart reviews and direct interviews for the purpose of comparing stated attitudes and actual clinical practices. An excellent technique which provides hard objective data, but is limited in terms of both the limited scope of questions it answers, and the much higher cost per respondent.

(c) Mailed questionnaires provide a relatively low cost data collection mechanism, but are troubled by lower response rates among the selected population (one study in New York State had a fairly impressive 53% return),...and are subject to greater variation in how questions are read and interpreted by the respondents. Response rates can be increased by employing elaborate follow-up "reminder" systems without sacrificing the anonymity of the respondent, but this makes the process significantly more complex and increases the time required for completion of the survey.

Table 1:
Examples of published studies

Subject of Study	Method Used	N	Population	Date
Practices in primary care prevention.....	phone interviews	120	Primary care physicians (NYC)	1984
Ca detection attitudes and practices.....	phone interviews	1035	Primary care physicians (US)	1984
Prevention/scrng. stds. vs. physician practices..	Record reviews & patient interviews	83	Physicians (Mass)	1982
Performance on 7 Ca screening tests.....	Record reviews & MD interviews	52	Internists (Calif)	1981-82
Mammography scrng....	Mailed question're	370 (of 509)	Family phys.(NY)	1982

We decided to proceed with the simplest and least expensive option for the "broad brush" initial phase of our study:

During October, 1989, an alpha test of the questionnaire was done at the Sells Service Unit, with distribution of 29 questionnaires to physicians, clinical nurses and public health nursing staff. Comments were invited on the structure, understandability and pertinence of the questions, as well as having respondents complete the questionnaire. Thirteen responses were received for a 45% return. No respondent offered suggestions for change in the format or reported experiencing any difficulty in completing it.

Thus, in November, general distribution was made by mail to the two target IHS Areas with a franked return envelope addressed to the principal investigator. Return envelopes were coded to identify the geographic IHS Area of the respondent while preserving their anonymity. Recipients of the questionnaire were selected by their job title and functional location in the health care delivery system, with the intent of reaching those most directly associated with the screening and treatment of women subject to cervical and breast cancer. The group consisted of medical officers and nursing staff (except LPNs and Nurse Aids) assigned to general outpatient clinics and medical/surgical inpatient wards, nurse midwives, nurse practitioners, physician's assistants, community health nurses, and just a handful of "special interest" folks such as general surgeons, nursing health educators or discharge planners were included.

Table 2
Questionnaire Distribution

Location	Physician	Mid-level pract'ners	Clinical Nursing	PHNs & Others	Totals
PIMC	28		5	35	7
Keams Canyon	8	1	12	5	
Owyhee	4	1	5	2	
Sacaton	7	1	11	3	
San Carlos	3	2	12	5	
Schurz	7	3	4	4	
White River	11	3	33	8	
Cibeque	2	0	2	1	
Yuma	4	0	9	1	
Phoenix Area:	**74**	**16**	**123**	**36**	**249**
Chinle/Tsaile	23	9	35	8	
Crownpoint	12	3	22	6	
Ft. Defiance	13	6	36	7	
Gallup/Tohatchi	22	11	46	9	
Kayenta/Inscr. House	11	3	9	0	
Shiprock/Huerfano	24	9	44	13	
Tuba City	20	10	38	8	
Winslow	9	3	10	4	
Navajo Area:	**134**	**54**	**240**	**55**	**483**

Of the original mailing of 743 questionnaires, 11 were returned by the postal system "undelivered" due to transfer of the addressee to a new assignment and, therefore, are not included in the distribution displayed above. Ultimately, 307 of the 732 delivered questionnaires were completed and returned to the principal investigator. A somewhat typical, but disappointing, response rate of 41.94% overall. Those most likely to respond were apparently the community health categories (PHNs, health educators, discharge planners, etc.) who returned 69.2% those delivered. Nurses in active clinical roles, outpatient or inpatient, were the least likely to respond (and likely the busiest of the recipients), with 30.0% being returned. 42.3% of the physicians responded, and 44.3% of the so-called "mid-level" practitioners.

Since there was some concern over assuming that the 40+% who voluntarily responded actually represented the attitudes of the target provider group, a summary of the hard data and a questionnaire were sent to an accepted expert, Dr. Lee Sechrest at the psychology Department of the University of Arizona, for his evaluation. He commented that, even though the return was small, the absolute number was large enough and the questionnaire sufficiently straight-forward to draw conclusions which should be reasonable. He believes that "internal coherence" was present in the process and pointed out that, in other similar surveys, it has been hard to find substantial differences between responders and non-responders.

There was little difference in the response rate between IHS Areas, with 110 of 249 (44.58%) returned from the Phoenix Area providers and 196 of 483 (40.58%) from those in the Navajo Area.

A template was prepared in dBase III for input of the responses and a clerk assigned to enter the data. The data from the 307 coded questionnaires was analyzed through multiple computer runs as well as by careful review of the narrative comments which accompanied the objective responses.

D. Results

Response rates by categories: (% returned of those mailed out)

Phoenix Area:		Navajo Area:	
Physicians.....	35.1%	Physicians.....	46.3%
Mid-levels.....	50.0%	Mid-levels.....	42.6%
Clin. Nurses..	31.7%	Clin. Nurses...	28.3%
Community...	86.1%	Community...	61.8%

There was a considerable store of experience behind the data collected in this survey. Of the physicians responding, 76% were board certified in their specialty. Among the entire group of respondents, two-thirds were over 35 years of age and had greater than 5 years of clinical experience in their professional field. The median age of respondents was 39-40 years and they had a median of 9-10 years clinical experience.

Among both the Navajo and Phoenix Area respondents, 70% of the physicians were males, while the other professional subgroups were dominantly (79% to 89%) females. Only 70.6% of the Navajo physicians are board certified, as compared to 90% of the Phoenix Area doctors. The physician group tends to be the youngest (53% are 35 or under). The majority (69% to 73%) of the

other professional groups are over 35 years of age. As a group, the physicians also have less clinical experience (64% under 5 years) than the other professional groups (77% to 81% over 5 years).

Results: The following represents a summary of that analysis, taken question by question.

Question #1 - *What do you believe are the most significant reasons for poor health status in the population served by your service unit?*

	Most Signif.	Moderate Signif.	Average Signif.	Little Signif.	No Signif.
Inadequate access to curative health services	18	58	68	**72**	30
Inadequate patient understanding of prevention	**120**	**91**	36	7	1
Lack of jobs or economic opportunity	59	**88**	64	29	11
Alcohol and/or substance abuse	**130**	**71**	35	17	2
Inadequate budget for health programs	**85**	**87**	52	22	10
Insufficient skilled health care providers	33	49	54	**76**	2
Poor nutrition	47	**84**	**78**	37	6
Lack of educational opportunity	43	65	**90**	41	14
Poor housing	43	64	**82**	49	14
Environmental health problems	37	**78**	**83**	44	9
Inadequate sanitation	38	**80**	**70**	51	14
Community apathy	**73**	**85**	66	19	5
Bureaucratic incompetence	64	66	69	36	17

Those categories which prompted 70 or more positive responses are **boldface** to illustrate the dominant view that the principal causes of poor health status are alcohol or substance abuse, inadequate understanding of prevention, limited budget resources and community apathy. Also of interest is the perception among the provider group that access to health care and sufficient skilled providers are not major problems (keep in mind that this data is from the Phoenix and Navajo Areas), and recognition that socio-environmental factors such as jobs, nutrition, housing and sanitation are significant contributors to community health status.

In fact, there was a significant difference in emphasis in the rating of causes for poor health status between the Phoenix and Navajo Areas. Phoenix rated "alcohol and/or substance abuse" and "community apathy" somewhat higher than did Navajo providers. And Navajo providers understandably rated the importance of "lack of education", "poor housing", "sanitation" and "environmental problems" a bit higher than those in the Phoenix Area.

A careful analysis of all responses by demographic provider subgroups of gender, age, clinical experience and professional classification (physicians, mid-level practitioners, nurses and others) revealed some interesting insights:

- There was a general tendency for female respondents to rate all issues as more significant than their male counterparts.
- Respondents over age 35 were more likely to rate issues in the extremes (high or low), displaying a more "opinionated" position than those 35 or younger who tended to group more toward the middle rating values.
- In general, the more highly trained the provider, the lower their ranking of "poor nutrition" as a significant cause of poor health.

Question #2 - *What is your perception of the prevailing attitude toward preventive medicine among the providers at your service unit?*

On a scale of 0-"little interest" to 10-"enthusiastic", the mean response was **6.21**.
The most frequently selected value was **8** (second most frequent value **5**).

Those selecting high values:	Physicians.....	82.0%
(6 to 10 on a scale of 0-10)	Mid-levels.....	57.7%
	Nurses.....	66.3%
	Others.....	32.8%

This was the first of four questions (Q. #2, 3, 8 and 13), to which the response displayed a curious phenomenon. On all these offering a 0 to 10 scale, "peaks" of response tended to uniquely occur at the 3, 5, or 8 values. It would appear that respondents inadvertently chose to simplify the scale by opting for a "below average" (3), "average" (5), or "above average" (8) response.

As a rule, the younger providers were more positive in their rating of local attitudes toward prevention (only 27.8% scored 5 or less on a 0-10 scale), while those over age 35 expressed some comparative cynicism (43.2% scored 5 or less). yet, in responding to question #3 (below), the younger providers thought less effort was being devoted to early detection than did their counterparts over the age of 35. Navajo providers rated themselves higher on prevention than Phoenix providers.

Question #3 - *In your opinion, how much attention and effort is currently being directed to early detection of cancer by the providers at your service unit?* (Separate responses were requested for breast cancer and cervical cancer.)

On a scale of 0 to 10, the mean response for breast cancer was **4.63**.
the most frequently selected value was **5** (second most frequent value **3**).

On a scale of 0 to 10, the mean response for cervical cancer was **5.79**.
the most frequently selected value was **5** (second most frequent value **8**).

Note: A minority of responses assigned the same value to both categories, but most responders rated the attention given to detecting breast cancer 2 to 4 integers below that for cervical cancer.

Question #4 - *Do you think IHS should establish "dedicated" clinic sessions with specially trained female staff (NPs) as women's health providers for the sole purpose of dealing with reproductive health issues, such as family planning, breast/cervical cancer screening, STD screening, prenatal care, breast-feeding and counseling on parenting matters?*

Yes - **210** (81.4%) No - 27 Undecided - 21

This was one of the most consistently positive responses to the questionnaire, yet marked by some polarization. Most of the positive reactions were accompanied by a narrative statement about female patients being more comfortable with female providers, and urging the provision of a setting to accommodate this sensitivity. Some of those opposed to this approach expressed concerns over further "fragmentation" of the delivery system.

There is a slight negative bias revealed among the under age 35 providers (physicians?), and some apparent gender bias. While only 14.1% of females answered "no" or "undecided", that count among the male respondents was 27.8%. By professional groups, the "yes" responses were:

physicians.....	71%
midlevels.....	88%
nurses.....	79%
others.....	95%

Question #5 - *Where do you think screening for breast and cervical cancer is most effectively accomplished?*

	General Outpatient Clinic - **105**
Emergency Room - 8	Women's Clinic - **188**
Inpatient Admissions - 40	Prenatal/Gynecology Clinic - **171**

This requires little comment. There was little or no difference of response to this question based on gender, geographic location, age, experience of professional subgroup.

Question #6 - *Should IHS adopt a set of screening and follow-up standards for use by all IHS providers? Or is it better to rely on the clinical judgement of each provider in their own setting?*

Develop IHS standards that all IHS providers will be required to use - **119**
Develop IHS standards only as a guide for individual judgement - **126**
Allow individual providers to apply their own standards and preventive methods - 9

Almost no one pointed out that we already have existing IHS standards in place, but the response reflected an impressively even split between the hard-line rule followers and those providers who need a bit more "elbow room" in their practice. Generally, over age 35 providers, females and the Phoenix Area providers tended to favor required use of the IHS screening standards, while younger providers, males, and those on the Navajo Reservation prefer establishing standards only as a guide for clinical practice. There was a readily evident attitudinal split between the professional subgroups:

Physicians strongly prefer guidelines only (78%)
Mid-levels and Others prefer required standards (61- 72%), and
Nurses split evenly between the two.

Question #7 - *Below are some generally accepted screening recommendations for early detection of cervical and breast cancer in asymptomatic women. Please indicate with a check mark which you actually follow in your practice, and which might be unrealistic in your present setting.*

	Age	Frequency	Actual Practice	Unrealistic
Pelvic exam	20-65	annually	**139** (67.8%)	66
Pap smear	20-65	Q 3 yrs. after 2 init. neg. exams	**155** (80.7%)	37
Breast self-exam	>20	monthly	**131** (66.5%)	66
Breast MD exam	20-40	Q 3 yrs.	**149** (79.3%)	39
	>40	annually		
Mammography	35-40	baseline	43 (23.0%)	**144**
	40-50	Q 1-2 yrs.		
	>50	annually		

A significant majority of responders were comfortable with the standards for pap smears and breast exams by the provider, and were troubled mostly by the time pressures in their clinic setting which make it difficult to carry them out. There was slightly less accord on the necessity of an annual pelvic exam and the efficacy of devoting busy clinic time to teaching BSE techniques.

The narrative comments accompanying the negative responses on the mammography standards made it clear that this was not a rejection of the screening standards, but an expression of the fact that this practice is "unrealistic" from the standpoint that they do not have the resources to get mammography done.

Question #8 - *Knowing that many women are reticent about submitting to pelvic or breast exams, based on personal discomfort or embarrassment, what is your honest assessment of the chances for improving early detection of breast and cervical cancer among Indian women?*

On a scale of 0 to 10, the mean response was **6.02**.
The most frequently selected value was **8** (second most frequent value **5**).

The older provider group assessed the chances of improving early detection with less optimism (53% chose 5 or less on a 0-10 scale, while only 28.6% of the younger group rated it that low). Also, females tended to rate either low or high on this question, while males gave more "normative" middle-ground responses. The full break-down of responses was as follows:

1 - 2.0%	6 - 8.3%
2 - 5.5%	7 - 13.8%
3 - 10.7%	8 - 19.0%
4 - 9.9%	9 - 4.3%
5 - 17.0%	10 - 9.5%

There was considerable "spread" in responses, and the disparity of attitude was true of all

There was considerable "spread" in responses, and the disparity of attitude was true of all professional subgroups. The answer to this question is so important, and the above data so amorphous, that this subject obviously needs further investigation in an attempt to resolve the true potential for change through intervention.

Question #9 - *Of the following, which do you believe are reasons that providers at your service unit may not routinely perform screening tests on their asymptomatic patients?*

	Always	Often	Sometimes	Seldom
Inadequate clinical space	30	70	78	72
Lack of time in busy schedule	**110**	**90**	46	7
Forgetfulness or inadequate reminders	20	69	**108**	54
Doubtful benefit of tests, considering cost	13	41	56	**138**
Risk of complications	1	11	39	**197**
Lack of provider interest in prevention	22	30	87	**111**
Questionable validity, sensitivity or value of screening test	5	18	76	**149**

On the whole, the older (over age 35) providers tended to rate all reasons for not performing screening tests more highly than the younger group. We can only speculate as to whether this might be an attempt at justification for doing less screening (see Q.13) or possibly a reflection of the stronger biases which were demonstrated in their responses to question #1. We also note that female providers tended to rate all reasons more highly than male providers.

The physician group emphasized the "inadequate clinic space", as well as the "lack of time in a busy schedule" which got high scores among all examined subgroupings. In comparing geographic areas, the "lack of time" and "inadequate space" issues were more of a perceived problem for the Navajo providers than for those in the Phoenix Area.

Question #10 - *At present, mammography is not widely utilized by IHS or private practitioners. Do you believe mammography would be generally accepted and utilized by the Indian women, if it were more accessible and available?*

Yes - **186** (72.1%)No - 20 Undecided - 52

Considerable indecision persists among our providers as to whether or not Indian women would readily utilize mammography as a screening methodology. The younger providers and the physician group were slightly more optimistic about the acceptance of mammography by Indian women, but there was relatively little difference in attitude between the various subgroups. Most notable is the degree of uncertainty among the women and non-physician respondents.

Question #11 - *Considering the high cost, do you think mammography would be an appropriate use of our limited budget funds?*

Yes - **138** (55.0%)No - 49 Undecided - 64

There is even greater skepticism among our providers about diverting tight resources into an expensive mammography screening program. Analysis of responses to this question revealed remarkably little difference in attitude between any of the subgroups....by age, gender, experience, location or professional training.

Question #12 - *Would you more frequently order mammography for your patients if it were more readily available?*

Yes - **183** (81.3%)No - 18 Undecided - 24

Responses from the female providers were heavier on the "undecided" or "no" response, and many of the female respondents commented that they were in support roles and not in a position to be ordering patient mammograms. Younger providers were somewhat more enthusiastic (87.5%) about ordering mammography, if funds were made available, than their older co-workers (77.7%). In any event, based on the highly positive response, we would be assured of high usage if funding were available for this purpose.

Question #13 - *On what percentage of your outpatient visits do you estimate you currently check to see what screening tests are needed,...then recommend or perform those tests?*

The most frequently selected value was **8** (81-90%)
The second most frequent value was **3** (31-40%).

0-10%	11-20%	21-30%	31-40%	41-50%	51-60%	61-70%	71-80%	81-90%	91-100%
19	**13**	**16**	**26**	**16**	**19**	**12**	**24**	**35**	**20**

Isn't this interesting? IHS providers assess their own screening activity as being somewhat less than consistent or ideal. There is no significant difference in this erratic distribution of responses based on age or geographic area. Physicians, mid-level practitioners and younger providers, in general, tend to rate themselves as more frequent screeners than their counterparts. Only 31.8% of those age 35 or under estimated that they check less than half of their patients for needed screening, while 52.5% of those over age 35 did so.

Question #14 - *Is the Patient Care Component (PCC) of the automated RPMS in use at your service unit?*

Yes - 61 (25.1%) No - 122 (50.2%) Don't know - 60 (24.7%)

Note: This question was intended only to channel the responder to either 14a or 14b, for inquiry into their means of alerting providers to needed screening. Many of those who "didn't know" if the PCC was in use at their service unit were field workers who have less interaction with the system. Also, many indicated a lack of familiarity with PCC since it was just being put into use.

Question #14a - *If Yes (61 responders), do you use the "health summary" as a reminder to:*

update immunizations - 40
do pelvic exams/pap smears - 33
do provider breast exams - 29
teach breast self-examination - 24
order needed lab work - 30
provide patient education - 30