

Race-specific results of Papanicolaou testing and the rate of cervical neoplasia in the National Breast and Cervical Cancer Early Detection Program, 1991–1998 (United States)

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Abstract

Objective: To describe differences in cervical screening and biopsy results by race or ethnicity from women in the National Breast and Cervical Cancer Early Detection Program (NBCCEDP).

Methods: We examined the percentage of abnormalities detected by Papanicolaou (Pap) tests and the rate of biopsy-diagnosed high-grade precancerous or cancerous lesions by racial or ethnic group.

Results: Almost half the 628,085 women screened were members of racial or ethnic minority groups. American Indian or Alaska Native women were more likely than others to report never having had a prior Pap test. American Indian or Alaska Native women had the highest proportion of abnormal Pap tests for first program screens (4.4%), followed by blacks (3.2%), whites (3.0%), Hispanics (2.7%), and Asians or Pacific Islanders (1.9%). Whites had the highest biopsy detection rate of high-grade lesions for first program screens (9.9 per 1000 Pap tests), followed by Hispanics (7.6), blacks (7.1), American Indians or Alaska Natives (6.7), and Asians or Pacific Islanders (5.4).

Conclusions: This program provides important data on the prevalence of cervical neoplasia among diverse populations. Our findings that black women with a high-grade Pap test were less likely to get a work-up are disconcerting and merit further study and ultimate correction.

Introduction

The incidence of invasive cervical cancer in the US has decreased significantly over the last 40 years, largely because of early diagnosis and treatment of precursor lesions [1, 2]. Still, in 2000 an estimated 12,800 new cases of invasive cervical cancer will be diagnosed and about 4600 women will die of the disease [1]. To be sure that cervical cancer rates continue to decline, efforts to detect and treat cervical intraepithelial neoplasia (CIN) should be intensified, particularly in women with no prior screening. This precancerous phase encompasses a spectrum of cellular abnormalities, from CIN I (mild

dysplasia) to CIN II (moderate dysplasia) to CIN III (severe dysplasia and carcinoma *in situ*) [3]. CIN I lesions have a high spontaneous remission rate; progression to invasive cancer is uncommon. A significant proportion of patients with CIN II will progress to CIN III and some will eventually develop invasive cancer, but spontaneous regression can occur. CIN III is a high-risk precursor for invasive disease [4]. CIN can be treated at any stage, but some experts recommend only monitoring CIN I lesions for persistence. Papanicolaou (Pap) testing plus follow-up treatment significantly reduces the incidence of cervical cancer and death from the disease [5].

In the US, analysis of surveillance data has shown that there are racial and ethnic differences in the incidence, mortality, and survival rates of patients with cervical cancer [6]. The highest age-adjusted incidence rate in the Surveillance, Epidemiology and End Results (SEER) areas was found among Vietnamese women (43.0 per 100,000), while the lowest incidence rate was

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reported in Japanese women (5.8 per 100,000). Incidence rates of 15.0 per 100,000 were found in both Alaska Native and Hispanic women, with black, American Indian (New Mexico) and white women having somewhat lower rates. Analysis of death certificate data showed black women having the highest mortality rate from this disease, more than twice the rate of white women. In terms of survival, rates are lower for American Indians and Hispanics, who have more advanced disease at diagnosis, than other racial or ethnic groups [7, 8]. Racial differences in cancer survival rates may be a function of socioeconomic status (SES), however, as in one study the survival pattern of blacks was similar to that for lower SES groups in general [9].

Despite existing racial and ethnic disparities in cervical cancer incidence and mortality, the distribution of cervical cancer precursors by race and ethnicity has not been widely characterized. In this analysis, we examine differences by race and ethnicity in the results of cervical cytology screening and follow-up biopsy among medically underserved women screened by the National Breast and Cervical Cancer Early Detection Program (NBCCEDP) [10]. We particularly emphasize biopsy-confirmed high-grade lesions (*i.e.* CIN II or worse).

Subjects and methods

The NBCCEDP was established as a response to the Breast and Cervical Cancer Mortality Prevention Act of 1990 (Public Law 101-354) with the goal of increasing access to cancer screening services for low-income and uninsured women [10]. General overviews of the clinical outcomes of both breast and cervical cancer screening in the program have been published previously [11, 12]. Administered by the Centers for Disease Control and Prevention (CDC), the program has implemented cooperative agreements with state and territorial health agencies as well as American Indian or Alaska Native tribal programs to provide screening, referral, and follow-up services for medically underserved women. Since March 1998, CDC supports breast and cervical cancer screening services in 50 states, the District of Columbia, five US territories, and 15 American Indian or Alaska Native programs.

In collaboration with its state partners, CDC developed a set of standardized data items to monitor NBCCEDP's screening, diagnostic, and follow-up activities. For each woman receiving a cervical cancer screening examination in this program, information is collected from her clinical provider on her demographic characteristics and results of Pap tests. For those with abnormal screening results, information on diagnostic

procedures and final diagnosis is also collected. The formats and methods used for data collection vary among programs; however, the data categories are standardized before they are reported electronically to CDC twice a year. Race and ethnicity of women in the program are reported according to the classification system used by the Bureau of the Census under the Office of Management and Budget's Directive 15 [13]. For this analysis, if a patient indicated Hispanic ethnicity, she was classified as Hispanic, regardless of racial classification.

Women who did not identify themselves as Hispanic were classified according to race (white, black, Asian or Pacific Islander, American Indian or Alaska Native). We included in the totals: (1) women whose ethnicity was indicated as not Hispanic or unknown, and (2) women whose race was listed as "Other" or unknown, but did not present them separately.

The CDC requires laboratories to use Bethesda System categories [14] in reporting Pap test results: normal, infection/reaction, atypical squamous cells of undetermined significance, low-grade intraepithelial lesion, high-grade intraepithelial lesion, squamous cell cancer, and other. The Pap test results examined for this analysis are those reported for women whose first screen in the program ("first round") occurred between July 1991 and March 1998. For women who received more than one Pap test within this time frame, results from all Pap tests after the first are reported as "subsequent rounds". In addition to Pap test results, biopsy results and information on CIN and invasive cancers detected are also reported separately for first and subsequent rounds. Only subsequent Pap tests that occurred more than 90 days after the previous program Pap test are included, to avoid counting women under surveillance for an abnormal result.

For purposes of this analysis, Pap test results were considered abnormal if they were reported as low-grade intraepithelial lesion, high-grade intraepithelial lesion or squamous cell cancer. The percentages of abnormal results detected by Pap tests and the detection rate (per 1000 Pap tests) of biopsy-confirmed precancerous and cancerous lesions were calculated by racial or ethnic group. For the detection rate of high-grade lesions, we combined biopsy results of CIN II, CIN III/CIS, and invasive cancer (CIN II+).

History of a previous Pap test was collected for each woman in the program. Response categories are "yes", "no", or "unknown". Whether or not a woman had a previous Pap test was examined for all women, for women whose first NBCCEDP test was abnormal, and for women whose first program test resulted in a final diagnosis of CIN II +. These results were examined by race or ethnicity.

Positive predictive values were computed to obtain the percentages of high-grade Pap tests resulting in final diagnoses of high-grade histologic abnormalities. For this analysis, the positive predictive value is defined as the number of Pap tests with results of high-grade intraepithelial lesion or squamous cell cancer that result in histologically diagnosed CIN II+, divided by the number of Pap test results of high-grade intraepithelial lesion or squamous cell cancer.

Age-adjusted results were calculated by the direct method [15] using the age distribution of the 1995 NBCCEDP-screened population. The age-specific and age-adjusted detection rates were computed for each racial or ethnic group for the age categories 18–29, 30–39, 40–49, 50–59, and 60+ years. Ninety-five percent confidence intervals for proportions were calculated based on the normal approximation to the binomial distribution and the age-adjusted intervals using the direct standardization method.

Results

A total of 628,085 women (mean age 45.6 years) received at least one Pap test between July 1991 and March 1998 (Table 1). Almost half of these women were members of racial or ethnic minorities. On average, American Indian or Alaska Native women were younger than the other racial or ethnic groups.

Table 1. Age distribution of women receiving Pap tests through NBCCEDP (July 1991–March 1998) by racial/ethnic group

	All ^a	White	Black	A/PI	AI/AN	Hispanic
Number of women	628,085	329,557	90,844	18,055	50,368	128,616
Percent distribution	100	52.5	14.5	2.9	8.0	20.5
Age category (in years, %)						
<18	1.4	1.1	0.7	0.4	3.6	1.7
18–29	14.6	13.2	11.2	7.7	25.8	17.2
30–39	15.2	13.4	13.5	10.5	23.2	18.8
40–49	28.4	28.6	29.3	31.8	22.2	29.0
50–59	22.9	23.5	25.1	29.1	14.3	22.1
≥60	17.5	20.2	20.2	20.5	10.9	11.2
Average age	45.6	46.9	47.5	48.7	39.5	42.9

^a p -Value^b = 0.01.

Abbreviations: A/PI, Asian or Pacific Islander; AI/AN, American Indian or Alaska Native.

^a Includes 10,645 women of other/unknown race/ethnicity.

^b p -Value for difference in mean years of age across racial/ethnic groups derived from analysis of variance test.

The results of the Pap test for first and subsequent rounds of screening are shown in Table 2. In the first round, the age-adjusted percentage of abnormal Pap tests was 3.0% (95% CI 2.9–3.0%). American Indian or Alaska Native women had the highest percentage of abnormal first tests followed by blacks, whites, Hispanics, and Asians or Pacific Islanders. For subsequent rounds a similar pattern was seen with lower percentages. Differences by race or ethnicity in the percentage of abnormal Pap test results were due primarily to differences in the percentage of Pap tests read as low-grade intraepithelial lesions. Differences by race or ethnicity in the percentage of abnormal results follow the same pattern as the atypical squamous cells of undetermined significance results.

After the first screening round, 24,188 women received a diagnostic evaluation; this included all categories of Pap test results (including normal and infection/reaction). Over 90% of these evaluations included colposcopy (data not shown). Other procedures that may have been performed on the remaining 10% included endocervical curettage, excision of endocervical polyps, diagnostic conization, and biopsy of other structures such as vagina and vulva. Of women undergoing colposcopy, the biopsy report for 54% indicated no CIN; for 24% CIN I; for 21% CIN II/III/CIS; and 1% invasive cancer. There were 9973 women who received a diagnostic evaluation in the subsequent screening rounds again with over 90% including a colposcopy; 65% indicated no CIN; 22% CIN I; 12% CIN II/III/CIS; and 1% invasive cancer.

The age-specific and age-adjusted rates of biopsy-diagnosed CIN II+ (cases per 1000 Pap tests) for the five age categories are presented in Table 3 by race or ethnicity and screening round. Among all racial or ethnic groups, the age-specific rates decreased with increasing age in both the first and subsequent rounds. The overall age-adjusted rate was 8.3 (95% CI 8.1–8.6) for the first round and 4.7 (95% CI 4.5–5.0) for the subsequent rounds. In both instances, white women had the highest age-adjusted rate.

Overall, there were 365 cases of invasive cancer, an age-adjusted detection rate of 0.6 per 1000 Pap tests. There were 311 cases of invasive cancer in the first round and 47 in subsequent rounds. Seven of the cases in the subsequent rounds were not counted because the first and subsequent Pap tests were less than 90 days apart. The age-adjusted rates for first and subsequent rounds combined were not appreciably different across racial or ethnic groups: white (0.6), black (0.5), Asians or Pacific Islanders (0.7), American Indian or Alaska Native (0.6), and Hispanic (0.6).

Seventy percent of women in this program reported having had a Pap test before enrollment (Table 4). Less

Table 2. Percent distribution of first and subsequent Pap test results by racial/ethnic group

	Race/ethnicity					
	All ^a	White	Black	A/PI	AI/AN	Hispanic
First Round						
Total Paps (n)	628,085	329,557	90,844	18,055	50,368	128,616
<i>Pap results (%)</i>						
Normal	80.7	83.1	73.5	85.8	71.1	82.7
Infection/reaction	9.9	8.1	17.9	7.8	13.4	7.9
ASCUS	4.9	4.7	4.6	3.7	7.7	4.8
LSIL	2.3	2.1	2.1	1.0	4.6	2.1
HSIL	0.8	0.8	0.7	0.5	0.9	0.8
SqCa	<0.1	<0.1	<0.1	<0.1	<0.1	<0.1
Other	0.5	0.5	0.4	0.3	0.5	0.4
Unsatisfactory	0.8	0.6	0.7	0.8	1.7	1.2
Adjusted total abnormal ^b Pap % (95% CI)	3.0 (2.9–3.0)	3.0 (2.9–3.0)	3.2 (3.0–3.3)	1.9 (1.6–2.1)	4.4 (4.2–4.6)	2.7 (2.6–2.8)
Subsequent rounds						
Total Paps (n)	313,872	174,354	41,542	6,827	31,502	56,923
<i>Pap results (%)</i>						
Normal	80.4	83.5	73.9	85.2	67.5	82.3
Infection/reaction	10.8	8.5	18.0	8.5	17.6	9.0
ASCUS	5.6	5.3	5.2	4.1	8.6	5.4
LSIL	1.7	1.4	1.5	1.0	4.4	1.5
HSIL	0.4	0.3	0.3	0.2	0.6	0.4
SqCa	<0.1	<0.1	<0.1	<0.1	<0.1	<0.1
Other	0.4	0.5	0.5	0.3	0.4	0.3
Unsatisfactory	0.6	0.5	0.6	0.7	0.9	1.0
Adjusted total abnormal ^b Pap % (95% CI)	2.4 (2.4–2.5)	2.2 (2.1–2.3)	2.7 (2.4–2.9)	1.8 (1.3–2.3)	4.1 (3.9–4.4)	2.1 (1.9–2.2)

Abbreviations: A/PI, Asian or Pacific Islander; AI/AN, American Indian or Alaska Native; CI, confidence interval; ASCUS, atypical squamous cells of undetermined significance; HSIL, high-grade intraepithelial lesion; LSIL, low-grade intraepithelial lesion; SqCa, squamous cell cancer.

^a Includes 10,645 women of other/unknown race/ethnicity.

^b Includes LSIL, HSIL, and SqCa; age-adjusted to 1995 NBCCEDP population.

than half of the American Indian or Alaska Native women reported a previous Pap test; percentages were higher for other groups, with rates for all but Asian or Pacific Islander women (55%) being above 70%. Of the American Indian or Alaska Native women who had an abnormal Pap test result on the first program screen, 57% reported no previous Pap test prior to enrollment. In addition, 55% of the American Indian or Alaska Native women who had a biopsy-confirmed diagnosis of CIN II+ reported no previous Pap test. In both analyses, the percentages for American Indian or Alaska Native women were much higher than for those in the other racial or ethnic groups.

The positive predictive values of a high-grade Pap test (high-grade intraepithelial lesion or squamous cell cancer) for biopsy-confirmed CIN II+ are reported in Table 5. In the first round, 64.2% of the high-grade abnormal Pap tests led to this diagnosis. Consistent with the relationship between positive predictive values and disease prevalence, the positive predictive value was

lower (53.2%) in the subsequent round. Positive predictive values were highest among white women in the first round and Asian or Pacific Islander women in the subsequent rounds. Positive predictive values were lowest for American Indian or Alaska Native women in first and subsequent rounds.

Discussion

Few reliable population-based data are available on the prevalence of premalignant lesions of the cervix or their distribution by racial or ethnic categories. Furthermore, although the National Cancer Institute's SEER program has been collecting incidence data on *in-situ* lesions of the cervix uteri since 1973, the data have not often been used [16]. In addition, as relevant terminology in both pathology and cytology has changed over time, comparing data from different time periods is often difficult.

Table 3. Age-specific and age-adjusted rates^a of biopsy-confirmed high-grade cervical intraepithelial neoplasia or invasive cancer, by race/ethnicity and screening round

	Race/ethnicity					
	All ^d	White	Black	A/PI	AI/AN	Hispanic
First round						
Cases ^b	5424	3151	597	88	441	1095
Age category (in years, %)						
18–29	23.6	31.8	18.9	12.3	12.4	17.2
30–39	13.7	16.5	11.2	4.8	9.5	12.6
40–49	5.3	5.8	4.4	2.8	4.9	5.2
50–59	3.5	3.1	3.6	4.9	5.0	3.8
≥60	2.8	2.0	3.1	5.1	4.5	5.0
Age-adjusted rate ^c (95% CI)	8.3 (8.1–8.6)	9.9 (9.5–10.2)	7.1 (6.5–7.7)	5.4 (4.2–6.6)	6.7 (5.9–7.4)	7.6 (7.1–8.0)
Subsequent rounds						
Cases ^b	1256	721	117	15	177	212
Age category (in years, %)						
18–30	13.8	16.6	13.8	0.0	12.8	9.6
30–39	7.6	9.8	4.2	1.6	5.6	6.4
40–49	3.1	3.4	2.6	3.0	2.7	2.6
50–59	1.8	2.0	1.4	2.2	1.8	1.5
≥60	1.6	1.3	2.2	1.8	1.7	2.5
Age-adjusted rate ^c (95% CI)	4.7 (4.5–5.0)	5.6 (5.1–6.0)	4.0 (3.1–4.9)	1.9 (0.9–3.0)	4.2 (3.5–4.9)	3.8 (3.3–4.3)

Abbreviations: A/PI, Asian or Pacific Islander; AI/AN, American Indian or Alaska Native; CI, confidence interval; CIN, cervical intraepithelial neoplasia; CIS, carcinoma *in-situ*.

^a Rates calculated per 1000 Pap tests.

^b Number of women with CIN II, CIN III, CIS or invasive cancer.

^c Age-adjusted to the 1995 NBCCEDP population.

^d Includes 82 women with other/unknown race/ethnicity.

The results reported here represent the only data available to date reporting race-specific precancerous detection rates using a standardized reporting system. The NBCCEDP represents one of the largest service delivery efforts for screening women for cervical cancer and precancerous lesions. This is not a population-based program, and thus our findings cannot be generalized to any racial or ethnic group as a whole. Only low-income women without insurance coverage are eligible for the program. Only about 12–15% of eligible women have undergone program-funded early detection services because there are insufficient funds available to CDC to expand the program to provide services to all eligible women. Although not population-based, NBCCEDP provides an important picture of cervical cytologic screening in different racial or ethnic populations, as the program operates in a variety of clinical settings throughout the nation and overrepresents racial or ethnic minorities. Because the women in this study were all low-income and uninsured, the racial differences we found may be less related to these important factors.

In this analysis of women enrolled in NBCCEDP between July 1991 and March 1998, American Indian or

Alaska Native women had the highest, and blacks the second-highest, age-adjusted percentage of abnormal Pap test results. Asian or Pacific Islander women had the lowest rate. Age-adjusted rates of biopsy-confirmed high-grade dysplasia (CIN II+) did not follow this same distribution pattern, however. In this instance, white women had the highest rates and Asian or Pacific Islander women the lowest. This difference in Pap test and biopsy results does not appear to be explained by the rates of diagnostic follow-up procedures performed for women with a Pap test result of high-grade intraepithelial lesions or squamous cell cancer. Of those women, 90% had a diagnostic work-up and percentages of women receiving a work-up were similar across racial or ethnic groups (Table 6). Blacks had the lowest percentage (83%), but this rate did not differ significantly from those in the other groups.

Every woman with a Pap result of high-grade intraepithelial lesions or squamous cell cancer should receive some type of diagnostic work-up, such as a colposcopy or other recommended procedure. However, the current recommended follow-up and treatment for low-grade intraepithelial lesions and atypical squamous cells of

Table 4. Percent distribution of prior Pap test by race/ethnicity and screening outcome

	Race/ethnicity					
	All ^a	White	Black	A/PI	AI/AN	Hispanic
Of all Women						
Number of women	628,085	329,557	90,844	18,055	50,368	128,616
Prior Pap (%)						
Yes	69.6	73.2	71.1	54.9	47.6	71.0
No	10.6	5.1	6.3	27.0	35.1	15.9
Unknown	19.8	21.7	22.6	18.1	17.3	13.2
Of women with abnormal first program test^b						
Number of women	19476	9524	2642	284	2791	3890
Prior Pap (%)						
Yes	59.6	65.6	64.6	57.0	34.5	61.4
No	19.7	10.5	7.4	15.9	56.8	24.1
Unknown	20.7	23.9	28.0	27.1	8.7	14.5
Of women with CIN II+ following first program test						
Number of women	5424	3151	597	88	411	1095
Prior Pap (%)						
Yes	64.1	68.8	66.2	56.8	31.9	64.4
No	16.0	9.7	8.9	15.9	54.7	22.6
Unknown	19.9	21.5	25.0	27.3	13.4	13.1

Abbreviations: A/PI, Asian or Pacific Islander; AI/AN, American Indian or Alaska Native; CIN II+, cervical intraepithelial neoplasia II (includes CIN II, CIN III, carcinoma *in-situ*, and invasive cancer).

^a Includes 10,645 women with other/unknown race/ethnicity.

^b Test result of low-grade intraepithelial lesion, high-grade intraepithelial lesion, or squamous cell carcinoma.

undetermined significance is not standard, but risk-based and may require a follow-up Pap test and no immediate additional diagnostic procedure [2]. We were unable to assess the appropriateness of follow-up for low-grade intraepithelial lesions and atypical squamous cells of undetermined significance, because we lacked detailed information on risk factors. As would be expected, the percentage of women receiving a diagnostic work-up for low-grade intraepithelial lesions or

atypical squamous cells of undetermined significance was much lower than for high-grade intraepithelial lesions or squamous cell cancer (Table 6). The results concerning a diagnostic work-up for low-grade intraepithelial lesions were similar to those for high-grade intraepithelial lesions or squamous cell cancer, again with black women having the lowest percentage of follow-up. This pattern was not seen in the results for diagnostic work-up following a Pap result of atypical squamous cells of undetermined significance. The percentages were similar across racial or ethnic groups with the exception of a much lower percentage for American Indian or Alaska Native women (9.4%). The degree to which these variations in diagnostic follow-up may account for the racial variation in detection rates is uncertain.

Some of the variation in racial or ethnic patterns between Pap results and detection rates may have been due to differences in screening histories. For example, American Indian or Alaska Native women were less likely than those in other groups to report a Pap test before enrollment, and thus might have been expected to have a higher rate of abnormal tests. On the other hand, a high percentage of their abnormal tests were low-grade intraepithelial lesions which would not be expected to progress often to CIN II or worse [2]. Thus our findings that the rate among American Indian or Alaska Native women of biopsy-confirmed high-grade dysplasia was below that of other racial or ethnic groups may be unremarkable. Follow-up patterns are an unlikely explanation for the differential findings on American Indian or Alaska Native women, as they had the highest percentage of follow-up recorded for low-grade intraepithelial lesions and equivalent follow-up for high-grade intraepithelial lesions and squamous cell cancer results.

Overall in the NBCCEDP white women had the highest rate of biopsy-detected high-grade precancerous lesions, a finding that apparently does not accord with the SEER-reported national rates for invasive cervical

Table 5. Positive predictive values (%) with 95% confidence intervals for high-grade Pap tests^a by race or ethnicity and screening round

Screening Round	Race or ethnicity					
	All ^b	White	Black	A/PI	AI/AN	Hispanic
First	64.2 (62.8–65.6)	67.5 (65.6–69.4)	63.9 (59.9–67.9)	65.1 (54.8–75.3)	50.0 (45.2–54.8)	62.9 (59.9–65.9)
Subsequent	53.2 (50.1–56.3)	57.1(52.7–61.5)	55.5 (46.5–64.6)	61.5 (35.1–88.0)	44.5 (36.9–52.1)	49.1 (42.3–55.8)

Abbreviations: A/PI, Asian or Pacific Islander; AI/AN, American Indian or Alaska Native; CIN II+ cervical intraepithelial neoplasia II+ (includes CIN II, III CIS and invasive cancer).

^a Positive predictive value calculated as the number of high-grade (high-grade intraepithelial lesions; squamous cell carcinoma) Pap tests leading to a high-grade lesion by biopsy (CIN II+) divided by the total number of high-grade Pap tests.

^b Includes 10,645 women with other/unknown race/ethnicity.

Table 6. Percentage of women with abnormal Pap results of HSIL + or LSIL or ASCUS who had a diagnostic evaluation completed, by race or ethnicity

Pap result ^a		Race/ethnicity					
		All	White	Black	A/PI	AI/AN	Hispanic
HSIL or SqCa (n = 6023)	% Yes ^b	90.0 (84.3–95.8)	89.5 (85.5–93.6)	83.4 (76.6–90.2)	93.0 (73.4–100)	88.9 (78.9–98.8)	89.5 (83.6–95.4)
LSIL (n = 18,693)	% Yes ^b	65.6 (62.8–68.5)	63.7 (61.4–65.9)	48.7 (45.2–52.1)	62.9 (52.1–73.7)	67.9 (63.9–71.9)	62.6 (59.1–66.1)
ASCUS (n = 45,330)	% Yes ^b	21.5 (21.0–21.9)	21.1 (20.5–21.7)	21.2 (20.0–22.4)	24.9 (21.5–28.4)	9.4 (8.5–10.3)	22.6 (21.6–23.7)

Abbreviations: A/PI, Asian or Pacific Islander; AI/AN, American Indian or Alaska Native; HSIL +, high-grade intraepithelial lesion or SqCa, squamous cell cancer; LSIL, low-grade intraepithelial lesion; ASCUS, atypical squamous cells of undetermined significance.

^a First and subsequent screening rounds combined for the time period 1 July, 1991–30 September, 1997.

^b Age-adjusted to the 1995 NBCCEDP population with 95% confidence interval.

cancer, in which white women had a rate of cervical cancer slightly less than half that of black women [6]. One possible reason for this difference is that because the program accounts for SES, all women in this program are low-income women without insurance coverage. On the other hand, Hispanic women, who had one of the highest cervical cancer incidence rates in SEER, also had a high rate of precancerous lesions in the NBCCEDP. Moreover, Asian or Pacific Islander women in the NBCCEDP had a relatively low rate of precancerous lesions, which is consistent with the very low SEER-reported rate of invasive cervical cancer in Japanese women but not with the high rates in Vietnamese women (we were unable to examine subgroup-specific rates in the NBCCEDP).

Any study that investigates patterns by race or ethnicity bears the risk of substantial error from misclassification. Relative to this study, previous research has shown a problem with classifying American Indians or Alaska Natives, Asian Americans, Pacific Islanders and Hispanics [17]. A major source of this error in such studies is the discrepancy between interviewer observation and reporting by respondents [17]. In the NBCCEDP, racial and ethnicity categories are assigned to participants by self-report; even though some misclassification may result, the classification for both the numerator and denominator is from the participant, which should minimize misclassification overall. In the calculation of SEER rates, in contrast, race from the numerator comes from medical records while race in the denominator comes from self-report (through the US census).

One problem with making inferences from the NBCCEDP to US racial or ethnic groups generally is its reliance on particular areas. In the time period of July 1991 to March 1998, over 50% of American Indian or

Alaska Native participants were from New Mexico, and another 14% were from Alaska. In addition, over 50% of blacks in the program were from the Carolinas and Missouri. Almost 50% of the Asian or Pacific Islander women were from California. Finally, over 60% of the Hispanic women were from Texas, New Mexico, and California. Therefore, some of the differences in the rates that we are finding could be specific to the populations, providers, or data collection in these geographic areas rather than solely representing disease patterns within particular racial or ethnic groups.

Previous experience with Pap testing is an issue of great interest, and in this study we found that 70% of the women reported having had a Pap test before enrollment. We are unable to verify this percentage, however, and must concede the possibility of under- or over-reporting. The question may not have been asked similarly of all women enrolling in this program, or the participant may have not understood the question. A 1991 study based in a public health clinic suggested that women might wrongly assume that a Pap test is synonymous with having a pelvic examination; more than half incorrectly reported they had had a test [18].

Our study is predominantly a description of patterns of pre-invasive disease, as very few invasive cancers were detected. Examining the rates of pre-invasive disease across racial or ethnic categories among women enrolled in this program should provide useful information on follow-up and treatment of this disease. Follow-up is a vital part of the program which aims to identify pre-invasive disease, treat it, and prevent cancer. Our finding that only 83% of black women with a high-grade Pap test result had a diagnostic work-up is disconcerting. Albeit this rate did not differ significantly from those for other groups, there was a pattern for black women having a lower percentage of follow-up following a Pap result of

squamous cell cancer, high-grade intraepithelial lesion or low-grade intraepithelial lesion. The reasons why one out of six black women with a high-grade Pap test did not get a work-up are unknown but merit further study and ultimate correction. The NBCCEDP is committed to providing regular cervical screening and follow-up to high-risk underserved women of all racial or ethnic populations.

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