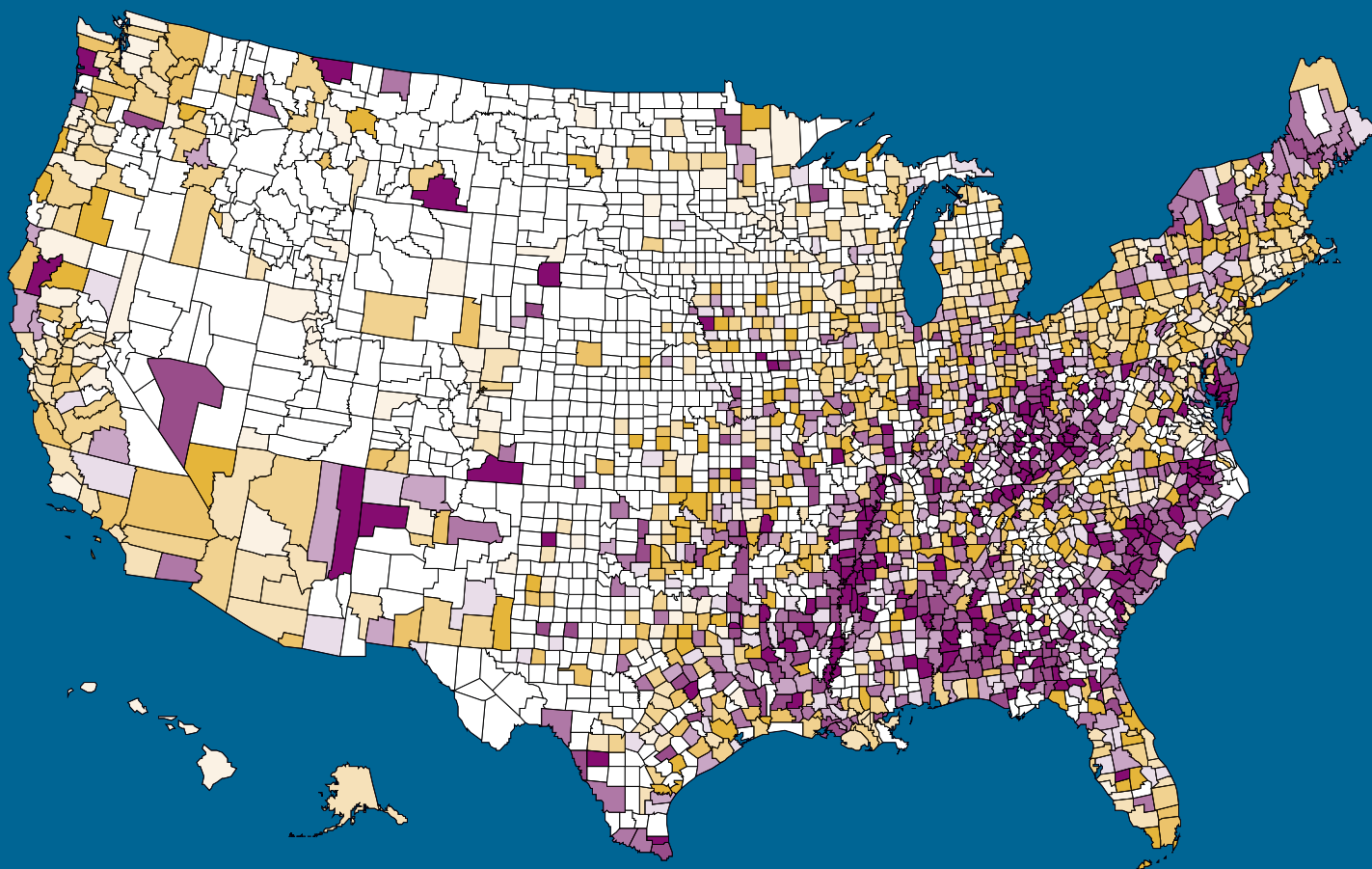


An Analysis

Excess Cervical Cancer Mortality

A Marker for Low Access to Health Care in Poor Communities

Center to Reduce Cancer Health Disparities



U. S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
National Institutes of Health
National Cancer Institute

Excess Cervical Cancer Mortality: A Marker for Low Access to Health Care in Poor Communities

NCI Center to Reduce Cancer Health Disparities

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Director's Message

A recent report identifying priority areas of health requiring national action,¹ including coordination of care, cancer screening, and self-management/health literacy, noted the stark fact that while “the United States spends more than \$1 trillion on health care annually [and has] extraordinary knowledge and capacity to deliver the best care in the world...we repeatedly fail to translate that knowledge and capacity into clinical practice.”

Nowhere is this failure of our health care system more apparent than in the disparities in cancer incidence and outcome, as well as in other health issues, suffered by members of particular racial and ethnic minority subgroups and other underserved populations. These disparities are grim realities resulting from the longstanding disconnect between (1) our extraordinary biomedical research discoveries and our ability to turn them into interventions that improve health and (2) our most distressing inability to deliver those interventions to all of the people who need them.

It is in this context that the National Cancer Institute's Center to Reduce Cancer Health Disparities (CRCHD) approached the problem of mortality from cervical cancer, a disease for which effective *prevention*—not just early detection—and treatment have existed for decades. Our failure to provide this lifesaving care to all women through appropriate infrastructure, information/communication systems, and adequate health care access highlights the urgent need to analyze our health care system—particularly publicly funded health services—and courageously craft the changes that will eliminate disparities and save lives.

Harold P. Freeman, M.D.
Director
National Cancer Institute
Center to Reduce Cancer Health Disparities

Executive Summary

Without question, cervical cancer is a success story in the history of cancer control. Since screening programs using the Papanicolaou test (Pap test) were implemented widely more than 50 years ago, cervical cancer deaths have declined 75 percent nationwide. Yet cervical cancer still takes the lives of approximately 4,000 women in the United States each year. This is particularly disturbing since virtually all cervical cancers should be avoidable with proper screening, and because effective treatment is available for precancerous lesions and for invasive cancers that are detected before they have spread.

The National Cancer Institute (NCI) Center to Reduce Cancer Health Disparities (CRCHD) postulates that cervical cancer is an indicator of larger health system concerns such as: infrastructure, access, culturally competent communication, and patient/provider education deficits that disproportionately affect members of particular racial and ethnic minority subgroups and other underserved women who also are subject to the negative effects of poverty on health status. Following a review of the scientific literature and available data on persistent cervical cancer mortality, CRCHD convened more than 180 Federal, state, and local planning and program personnel, policy-makers, researchers, clinicians, advocates, educators, and communications specialists as participants in its Cervical Cancer Mortality Project (CCMP) to explore the components of the problem, identify critical needs, and suggest actions to meet those needs.

An entrenched pattern of high cervical cancer mortality has existed for decades in distinct populations and geographic areas. Women suffering most severely from this disparity include African American women in the South, Latina women along the Texas-Mexico border, white women in Appalachia, American Indians of the Northern Plains, Vietnamese American women, and Alaska Natives. A more detailed analysis of two geographic regions where cervical cancer mortality is the greatest indicates that, in addition to needing targeted interventions and additional resources to reduce cervical cancer deaths, these communities also experience high mortality rates for other conditions and diseases for which screening and treatment are currently available.

A recent Institute of Medicine report² urges the Federal Government, using certain types of Federal health facilities as laboratories of innovation, to provide leadership in health care quality improvement efforts. In 2003, the Department of Health and Human Services (DHHS) chose to use the Progress Review Group (PRG) methodology to facilitate, promote, and coordinate partnerships among Federal agencies to address persistent cancer disparities, such as the excess cervical cancer

mortality rates in geographic regions and populations, implement new initiatives, and evaluate progress over time.

The NCI Center to Reduce Cancer Health Disparities recommends specific actions to eliminate cervical cancer mortality disparities suffered by women in identified geographic regions of the nation and to improve health care for all underserved women. Each major objective is listed with specific recommendations for reaching the goal. The recommendations are summarized on Table 1.

In this report, the NCI Center to Reduce Cancer Health Disparities demonstrates that high rates of cervical cancer are an indicator of broader problems in access to health care. The report argues that a high rate of cervical cancer is a *sentinel* marker indicating larger, systemic health care issues that need to be addressed by cancer control and other strategies. It also illustrates how the recommendations of the Report of the Trans-HHS Cancer Health Disparities Progress Review Group (CHPRG), *Making Cancer Health Disparities History* (<http://www.chdprg.omhrc.gov>), can be implemented to improve women's health in geographic areas experiencing excess cervical cancer mortality. The correspondence between our recommendations and those of the CHPRG recommendations are shown in Table 2.

Table 1. Strategies for Reducing Excess Cervical Cancer Mortality

Collaborations, Partnerships, and Advocacy

Establish and strengthen partnerships to promote “whole woman” approach to care.

Develop and implement an agenda to provide and sustain funding for coalitions, partnerships, and community-based quality health services, education, and prevention programs.

Research	Communications and Information	Access—Outreach, Services, Navigation
<ul style="list-style-type: none"> • Optimize HPV testing and HPV vaccine development to eliminate the primary biologic cause of cervical cancer. • Improve screening technologies and screening interventions to bring affordable screening to all women. • Conduct social/behavioral, health services, and intervention research to better understand high-risk populations and develop interventions to improve their care. • Improve data collection and surveillance activities related both to quantitative and to qualitative understanding of cervical cancer causes and control. 	<ul style="list-style-type: none"> • Improve awareness and knowledge about cervical cancer through the development and provision of linguistically and culturally appropriate information. • Improve provider-patient communication through provider education and availability of language translation. • Provide central resource detailing best practices for cervical and other cancers including evidence-based interventions. • Improve medical records maintenance and retrieval systems through the use of rapidly evolving information technology. 	<ul style="list-style-type: none"> • Intensify outreach to women who have rarely or never been screened for cervical, breast, or colon cancer and other screenable/treatable diseases. • Enable women who rely on publicly funded health services to have a “medical home”—a usual source of health care. • Provide patient navigators to help eliminate the disconnects between screening and follow-up treatment. • Increase the number of female providers of the patients’ gender/race/ethnicity. • Improve coverage and reimbursement for cancer-related services. • Improve the quality of care in rural areas through telemedicine and multidisciplinary consultations.

Table 2. Association of Eliminating Excess Cervical Cancer Mortality Recommendations With Priority Recommendations of the Trans-HHS Cancer Health Disparities PRG

Recommendations for Eliminating Excess Cervical Cancer Mortality

- Intensify outreach to women who have rarely or never been screened for cancer and other screenable/treatable diseases.
- Provide patient navigators to help eliminate the disconnects between screening and follow-up treatment.
- Improve screening technologies and screening interventions to bring affordable screening to all women.
- Increase the number of female providers of patients' gender/race/ethnicity.
- Increase coverage and reimbursement for cancer-related services.
- Improve the quality of care in rural areas through telemedicine and multidisciplinary consultations.
- Improve awareness and knowledge through the development and provision of linguistically and culturally appropriate information.
- Improve provider-patient communication through provider education and availability of language translation.
- Provide a central resource detailing "best practices" evidence-based interventions.
- Improve medical records maintenance and retrieval systems through the use of rapidly evolving information technology.
- Improve data collection and surveillance activities related both to quantitative and to qualitative understanding of cervical cancer.
- Enable women to have a "medical home"—a usual source of health care.
- Establish and strengthen partnerships that promote a "whole woman" approach to care.
- Develop and implement agenda to provide and sustain funding for coalitions, partnerships, and community-based quality health services, education, and prevention programs.
- Optimize HPV testing and HPV vaccine development to eliminate the primary biologic cause of cervical cancer.
- Conduct social/behavioral, health services, and intervention research to better understand high-risk populations and develop interventions to improve their care.

Priority Recommendations of the Trans-HHS Cancer Health Disparities PRG

- Ensure that populations at highest risk have access to age- and gender-appropriate screening and follow-up services.
- Develop, implement, and evaluate education and training programs designed to create a diverse and culturally competent cancer care workforce.
- Ensure that every cancer patient has access to "state-of-the-science" care.
- Support culturally, linguistically, and literacy-specific approaches for eliminating cancer health disparities. These should include evidence-based "best practices," proven interventions, and outreach strategies.
- Establish new approaches for data collection and sharing to aid in the study of the effects of cancer and its relationship to variables such as race and socioeconomic status.
- Collaborate with the private and voluntary health sectors to ensure that all Americans receive the full range of lifesaving information, services, and quality care.
- Increase the proportion of HHS agency support targeted specifically to disease prevention, health promotion, evaluation, and translational research on cancer health disparities.
- Establish partnerships for and support the development of sustainable community-based networks for participatory research in areas of high cancer disparities.

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Excess Cervical Cancer Mortality: A Marker for Low Access to Health Care in Poor Communities

An Analysis from the Center to Reduce Cancer Health Disparities (CRCHD)

Effectively addressing cervical cancer mortality can provide a model for action—an opportunity to address not only the health problems facing women who are dying from this disease but also the full set of human circumstances that lead to health disparities.

Women suffering high cervical cancer mortality also:

- Tend not to have a usual source of health care
- Are less likely to receive preventive health services, including cancer screening
- Have low incomes and educational attainment
- Have high rates of breast cancer, colorectal cancer, cerebrovascular disease, and infant mortality

CRCHD is the cornerstone and organizational locus of the National Cancer Institute's efforts to reduce the unequal burden of cancer in society. CRCHD oversees and coordinates the NCI's strategic plan to reduce cancer health disparities. Activities of the Center include health policy analyses and disparities research focusing on relationships among social, economic, cultural and environmental factors that cause or contribute to (1) the disproportionate cancer burden experienced by some populations and (2) the significant disconnect between research discoveries and the delivery of their benefits to all.

Cervical cancer is unquestionably a success story in the history of cancer control. Since cervical cancer screening programs using the Papanicolaou test (Pap test/Pap smear) were introduced more than 50 years ago, age-adjusted mortality from cervical cancer overall has declined three-fold. Because of the Pap test, which is inexpensive, easily administered, and effective, and because proven treatment for precancerous cervical lesions and localized invasive cancers is available,³ virtually all cervical cancer deaths should be avoidable. Pap tests find precancerous lesions that are easily and effectively treated with colposcopy or simply watched, since not all precancerous lesions become cancer. When cervical cancer is detected before it has spread, it is one of the most successfully treated cancers,⁴ though patients may suffer adverse consequences from treatment, including infertility and late effects of radiation and/or chemotherapy.

Recent research discoveries, including liquid-based cytology, a combined Pap test and test for the human papillomavirus (HPV) that causes most cervical cancers, and the development and testing of HPV vaccines promise to improve even further our ability to prevent or identify abnormalities of the uterine cervix long before they become cancerous. Still, in 2004 an estimated 3,900 women died from cervical cancer.⁵

Why Cervical Cancer Mortality Is Important

Despite the consistent decline in cervical cancer mortality overall, an entrenched geographic pattern of deaths from this disease has persisted for decades. This ongoing disparity in mortality from a wholly preventable disease drew the interest of the National Cancer Institute (NCI) and led the NCI Center to Reduce Cancer Health Disparities (CRCHD/the Center) to lead the inquiry into underlying factors that may contribute to the disparity. The NCI explored the hypothesis that in addition to being a cause of concern, endemic elevated cervical cancer mortality may be a marker or an indicator of weaknesses in the health care system infrastructure, particularly with respect to medical care access, cultural issues, and health communication and education issues that disproportionately affect poor and other underserved women. Most women living in areas with high rates of cervical cancer mortality rely on publicly funded programs for their health care. A recent analysis of selected SEER areas confirms that late-stage cervical cancer diagnoses are more likely in areas that are economically or socially distressed. The authors recommend that all distressed areas should automatically receive public funding.⁶ Poverty, in turn, is a human condition marked by substandard housing, lower educational attainment, subsistence-level employment, high unemployment, greater exposure to environmental toxins, and reduced access to health care. These conditions, occurring in a variety of urban and rural settings, also may affect health status significantly.

The Center further postulated that addressing issues related to cervical cancer in areas with high mortality from the disease also should result in improved overall health status and reduced mortality in these geographic regions. Women living in areas characterized by excess cervical cancer mortality also experience mortality rates above the national average for breast cancer, colon cancer, heart disease, stroke, and other conditions whose outcomes improve with regular screening or early intervention. Applying appropriate system improvements throughout publicly funded health services could have a broad-reaching effect on women's health nationwide.

CRCHD'S Cervical Cancer Mortality Project (CCMP)

This project was conducted in two major phases. The first phase focused on collecting and analyzing both historical and current data on cervical cancer incidence, screening, treatment, and mortality in the United States. In addition, a review of the literature published between 1966 and May 2001 (and some studies published between 1950 and 1965) on cervical cancer mortality among rural women was commissioned and is detailed in a report.⁷

From November 28–30, 2001, a Roundtable meeting was held in Corpus Christi, TX. The 144 participants (see Appendix A) included Federal, state, and local planning and program personnel; researchers from several disciplines with an interest in cervical cancer; clinicians;

advocates; educators; communications specialists; and NCI planning, cancer control, and CRCHD personnel. Findings from the data and literature reviews were shared with the participants.

Prior to the meeting, attendees were asked to participate in an online “concept mapping” exercise in which they submitted ideas for actions that would reduce cervical cancer mortality in their state or region. Some of the suggestions also were for actions at the national level. All of the ideas submitted were collated, redundancies were eliminated, and the ideas were sorted into conceptual categories. The condensed data were displayed on a “concept map” that identified clusters of related ideas. This map was presented to Roundtable attendees, who were asked to use the possible focus areas suggested by the clusters as the nucleus for one-year state action plans. On November 30, 2001, core members of the Cervical Cancer Think Tank met at the conclusion of the Roundtable meeting to review the suggested activities, actions, interventions, and policy changes in each of the four identified focus areas. The Think Tank members discussed possible priorities among the suggested actions, primarily at national and regional levels. All of the Phase 1 activities and outcomes were described in an interim report⁸ distributed to Roundtable participants, NCI staff, and others. The presentations made at that Roundtable meeting can be viewed at: <http://www.dccps.cancer.gov/d4d/info.html#conferences>. An Executive Summary of the Roundtable meeting is contained in Appendix A.

Following the completion of Phase 1 activities, it was decided that further exploration was needed to gain a better understanding of demographic, cultural, and environmental characteristics of specific populations in geographic areas experiencing high cervical cancer mortality in order to assess the potential impact of these factors on the burden from this disease. A Think Tank meeting was held in Bethesda, MD, in May 2002 (see Appendix B) bringing together several members of the group that convened in November 2001; added to this diverse group were other participants with specific experience and expertise in cervical cancer and with the populations most at risk. The group discussed factors specific to Appalachian and other rural whites; rural African Americans, particularly those in the Deep South; Latinas living near the Texas-Mexico border; and Vietnamese American and other Asian women, particularly those in California. Though little data was available and less is known about the causes of cervical cancer mortality disparities among Native Americans in the Northern Plains and among Alaska Natives, it was also acknowledged that these populations have higher than average cervical cancer death rates. Data from the 2001 California Health Interview Survey (CHIS) have been released and confirm lower rates of cervical cancer screening among Asian women, including Vietnamese (<http://www.healthpolicy.ucla.edu/pubs/publication.asp?pubID=85>).⁹

In October 2002, CRCHD staff and selected participants in the prior Think Tank and Roundtable meetings presented key project findings and issues to a group of senior officials

of Federal agencies that either administer or finance health services for underserved women (see agenda and participant roster, Appendix C). To illustrate the issues of geographic disparities in cervical cancer mortality, data specific to the Deep South and Appalachian regions were presented, but the discussion included all known affected populations. The focus of the meeting was to identify ways in which these agencies could better work together through collaborations and partnerships to provide improved and more consistent care to women needing (1) cervical cancer screening, diagnosis, and treatment services, and (2) care for other health conditions to which they are particularly vulnerable. The discussion also emphasized identifying interventions, health services, and policies that could be implemented using existing resources or, at most, minimal additional funding.

Current Knowledge About Cervical Cancer Mortality: Overview

Available statistics show clearly that while all women in America have benefited from the overall cervical cancer mortality reductions achieved over the past few decades, much remains unclear regarding the reasons for continuing mortality disparities and the best ways to address them. Data on the disparities and factors contributing to them are accumulating; however, much important information has yet to be collected.

Sources of Data on Cervical Cancer

Data on cervical cancer incidence and mortality are available from a number of national sources, including NCI's Surveillance, Epidemiology, and End Results (SEER) cancer registry program, the National Program of Cancer Registries (NPCR) of the Centers for Disease Control and Prevention (CDC), NCI's Atlas of Cancer Mortality in the United States, and the Medicare database. National studies such as the National Health Interview Survey (NHIS) conducted by the National Center for Health Statistics (NCHS), CDC's Behavioral Risk Factor Surveillance System (BRFSS), the American College of Surgeons (ACoS) National Cancer Data Base, and American Hospital Association (AHA) surveys provide additional information on risk factors, screening, and treatment.

In addition, the medical literature documents studies that explore biologic, socioeconomic, cultural, environmental, and other factors that may affect cervical cancer incidence and mortality. Some of these studies address selected regional, state, or local populations. Other studies on topics relevant but not specific to cervical cancer may be found in the social and behavioral sciences literature.

Several meta-analyses have examined specific aspects of cervical cancer prevention and care. However, as Yabroff et al.¹⁰ note, the published studies have such varied study designs

(e.g., sample selection and characteristics, response rates, method of ascertainment, definition of rural population) that data cannot be compared with confidence. In addition, few studies of screening distinguished between screening and diagnostic Pap tests or were corrected for hysterectomy or tubal ligation. As a result, the independent effects of age, social class, race, education, and geography on screening and mortality cannot be disaggregated, an endeavor further complicated by the racial, ethnic, age, and cultural heterogeneity of the affected populations.

Cervical Cancer Mortality in America

An overview of the available literature and data provide the following picture of cervical cancer in America:

Geographic Disparities

Women living in largely rural and suburban counties in states stretching from northern New England through Appalachia, in the Deep South, along the Texas-Mexico border, and in parts of the central valley of California have consistently higher rates of cervical cancer mortality than do women in other parts of the country (Map 1). Mortality rates have remained substantially higher in these areas over the past few decades, but rates have fallen somewhat even in these high mortality areas as rates have declined nationwide.

Sufficient information exists to pinpoint, by county, areas of high cervical cancer mortality for white and African American women. For African American women, high

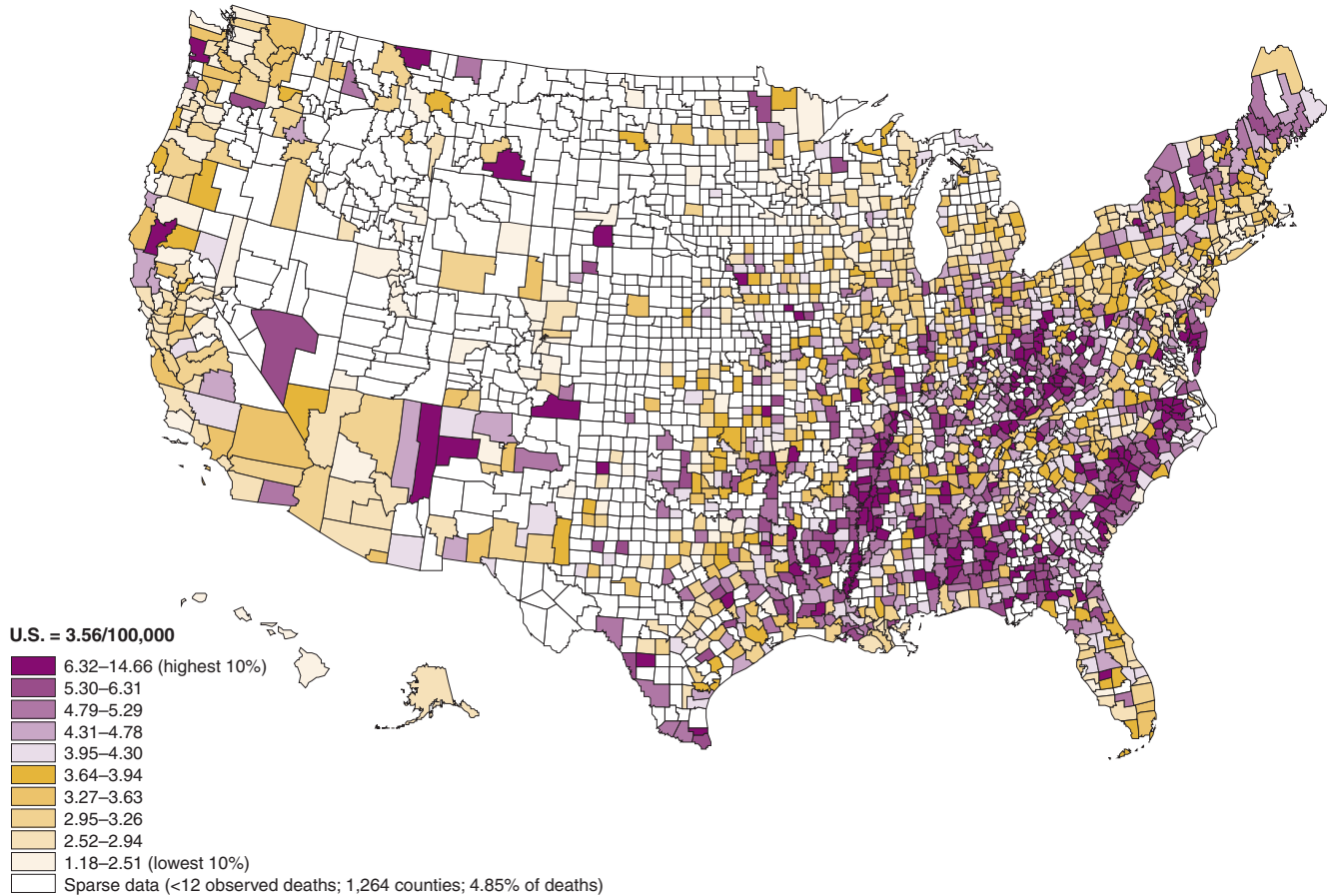
mortality areas tend to be rural. The geographic mortality pattern is similar among white women, but with a somewhat more suburban pattern. The data suggest an urban-rural gradient (i.e., mortality lower in urban areas, higher in rural areas) reflecting less access to care and poorer outcomes, though this has not been demonstrated clearly.¹¹

Racial/Ethnic Mortality Disparities

African American women suffer more than twice the number of cervical cancer deaths per 100,000 population compared with white women (Maps 2 and 3, pooled white and black data, 1970–1998). In fact, National Center for Health Statistics data now available for 1996–2001, adjusted to the 2000 U.S. standard million population, indicate that while the cervical cancer mortality rate for African American women has declined considerably to 5.7 per 100,000 population, it remains the highest rate of the major (census-defined) racial/ethnic populations and almost twice the rate of white women (3.4 per 100,000).¹² Rates are particularly high among black women in the rural South, but not among black women in the West.¹³

Cervical cancer mortality is higher than average among Hispanic/Latina women living on the Texas-Mexico border, and among white women in Appalachia, rural New York State, and northern New England. It also is known that American Indians of the Northern Plains and Alaska Native women have high cervical cancer mortality rates, but due to the small size of these populations and small number of cases relative to the total population, these differences are less

**Map 1. Cancer Mortality Rates by County (Age-adjusted 1970 U.S. Population)
Cervix Uteri: All Races, Females, 1970–1998**

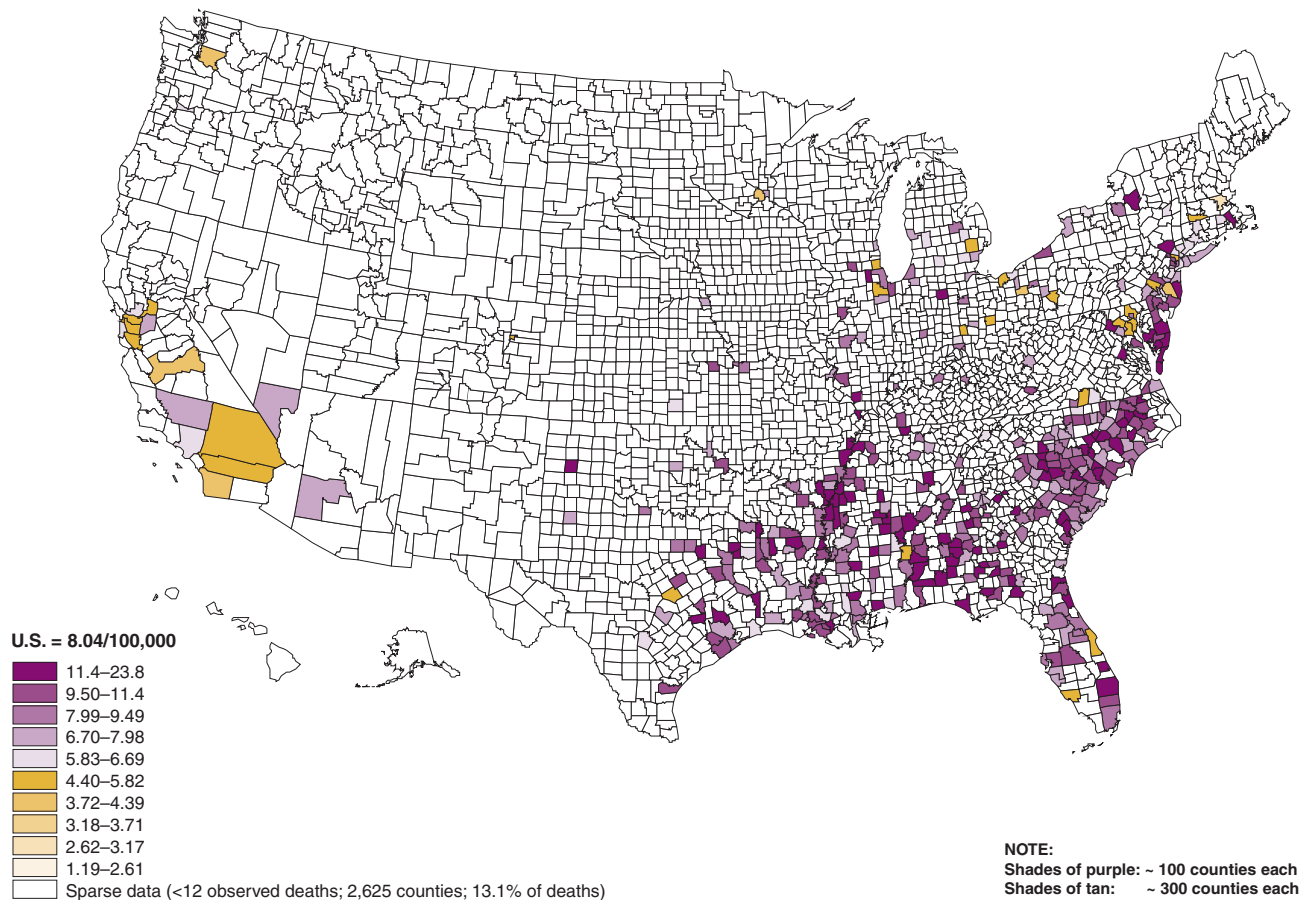


well documented, and maps depicting mortality patterns currently are unavailable. Cervical cancer incidence rates are five times higher among Vietnamese American women than white women.¹⁴ Data are beginning to emerge suggesting that overall rates of cervical cancer mortality among native-born women are declining, while rates among foreign-born women are increasing, particularly in the South. The reasons for the persistent disparities in cervical cancer mortality experienced by these populations have yet to be elucidated fully.

Socioeconomic Status (SES)-Related Mortality Disparities

As with other cancers, the risk of dying from cervical cancer increases with later stage at diagnosis. Available data, though limited, indicate that higher mortality is associated with lower income, less education, and lower SES overall. Among women diagnosed with stage I cervical cancer, only about 20 percent are those having lower educational attainment. Similarly, cervical cancer incidence rises with increasing poverty and decreasing SES across all racial ethnic

**Map 2. Cancer Mortality Rates by County (Age-adjusted 1970 U.S. Population)
Cervix Uteri: Black Females, 1970–1998; Pooled White and Black Rates**



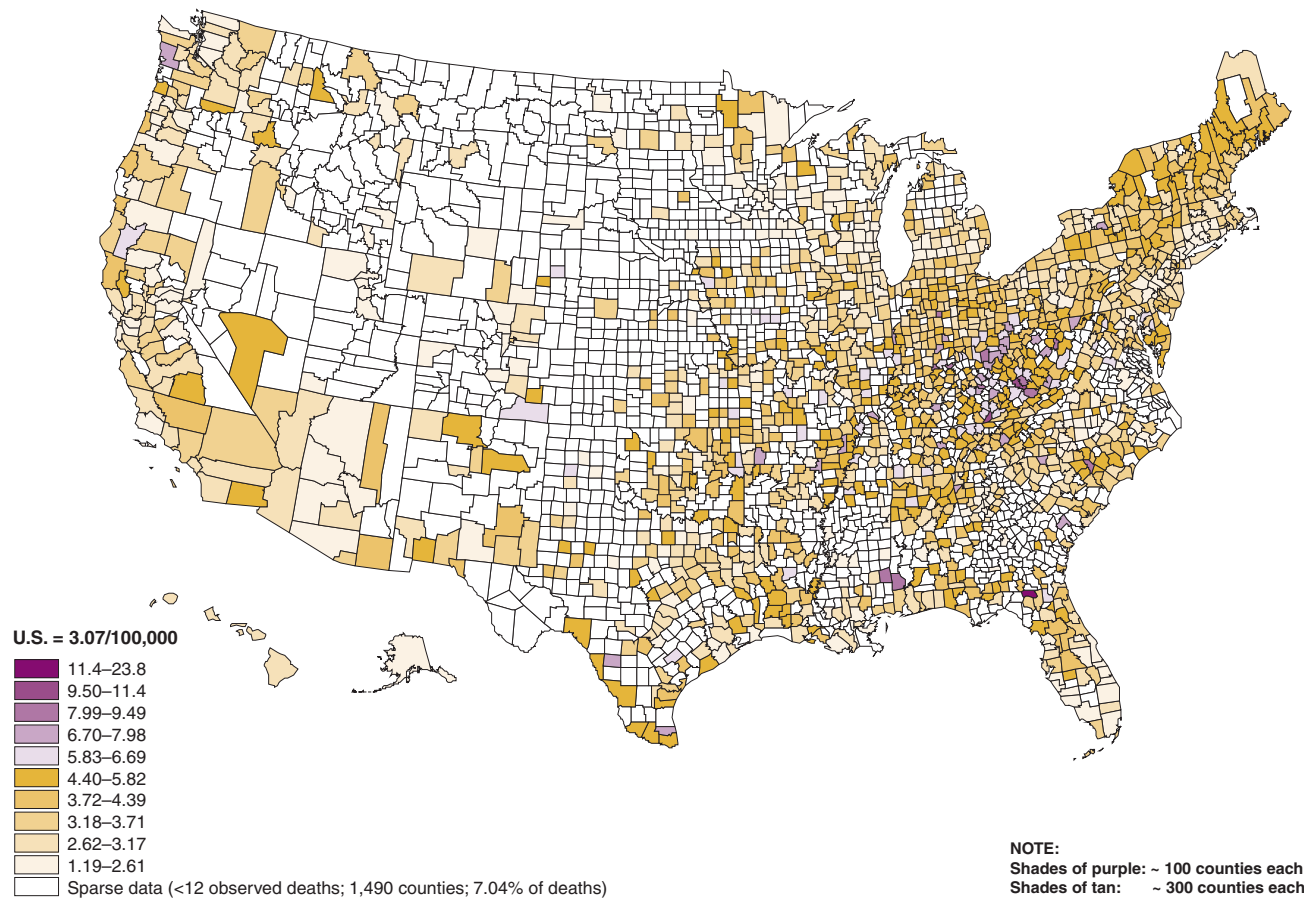
groups.¹⁵ Data on specific components of SES are being collected to a greater degree than ever before, but in most available cancer registry and other clinic-based data sets, race/ethnicity still is likely a proxy measure of SES. Surveys show that low SES is associated with lack of health insurance and other health care access factors.

The same populations of women that are experiencing high levels of cervical cancer mortality also are at risk for other screenable and treatable conditions. Maps 4, 5, 6, and 7 illustrate this situation clearly as it applies to

African American women in the Deep South (Alabama and Mississippi), and Maps 8, 9, 10, and 11 illustrate counties of excess mortality for white women in parts of Appalachia (West Virginia and Kentucky) respectively.¹⁶

In both areas, poverty levels are far above the national average, and these populations are characterized by lower educational attainment levels, geographic isolation, lack of transportation, greater exposure to environmental and occupational hazards, and poor housing.¹⁷ The women in these high cervical cancer mortality areas also experience excessive

**Map 3. Cancer Mortality Rates by County (Age-adjusted 1970 U.S. Population)
Cervix Uteri: White Females, 1970–1998; Pooled White and Black Rates**



mortality from breast and colorectal cancers, heart and cerebrovascular diseases, and high rates of infant mortality.¹⁸

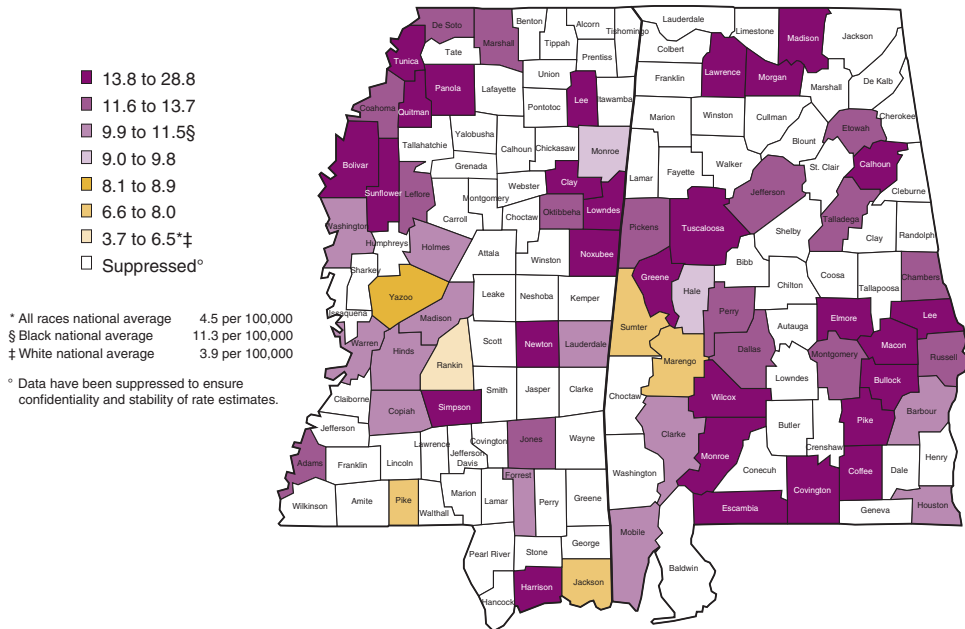
Although comparable data currently are not available for other populations with known high cervical cancer mortality rates, their disease patterns are believed to be substantially similar.

Cell Type

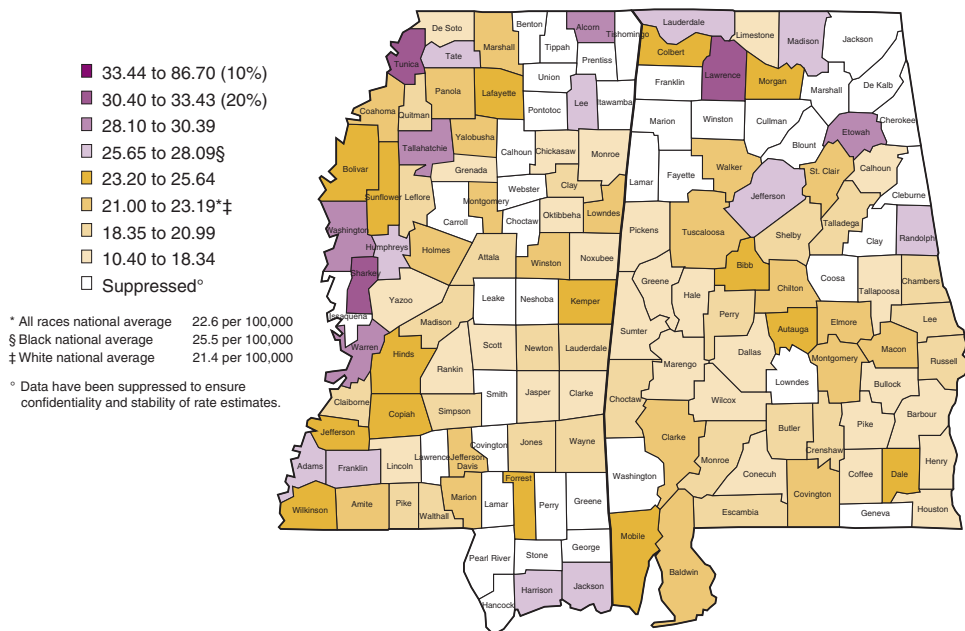
Most cervical cancers are squamous cell carcinomas. Nonsquamous cell cancers

(adenocarcinomas) now account for about 30 percent of cases. The proportion of all cervical adenocarcinomas has increased as the rates for squamous cell cancers have declined. Reducing mortality from cervical adenocarcinomas has been less successful than with squamous cell cancers. It is not yet known whether there is a relationship between high mortality geographic areas and the specific histology of the cervical cancers found there.

Map 4. Cervical Cancer Mortality Rate: Black Female, 1969–1999 (Alabama and Mississippi)

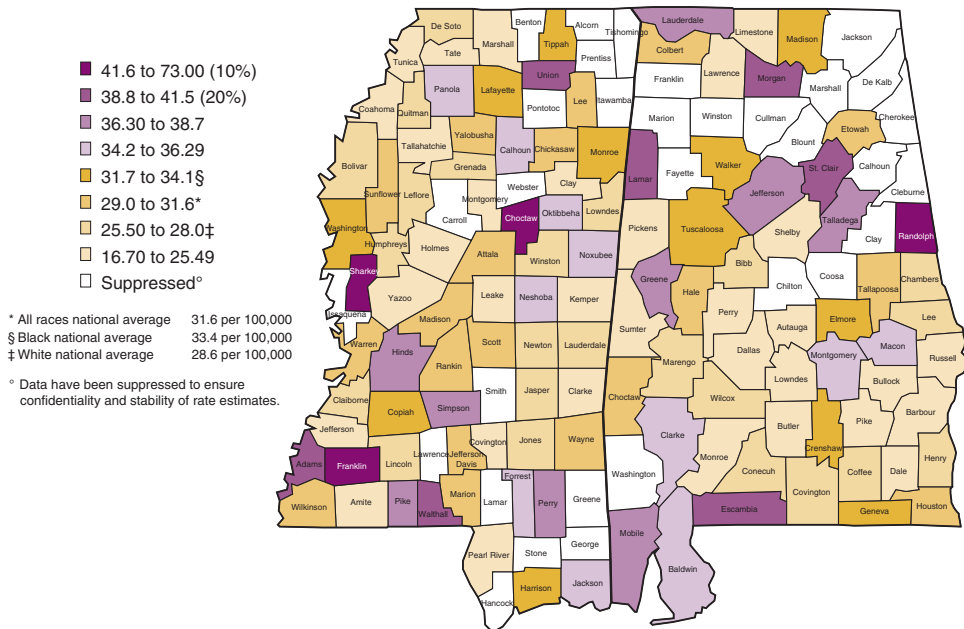


Map 5. Colon Cancer Mortality Rate: Black Female, 1969–1999 (Alabama and Mississippi)

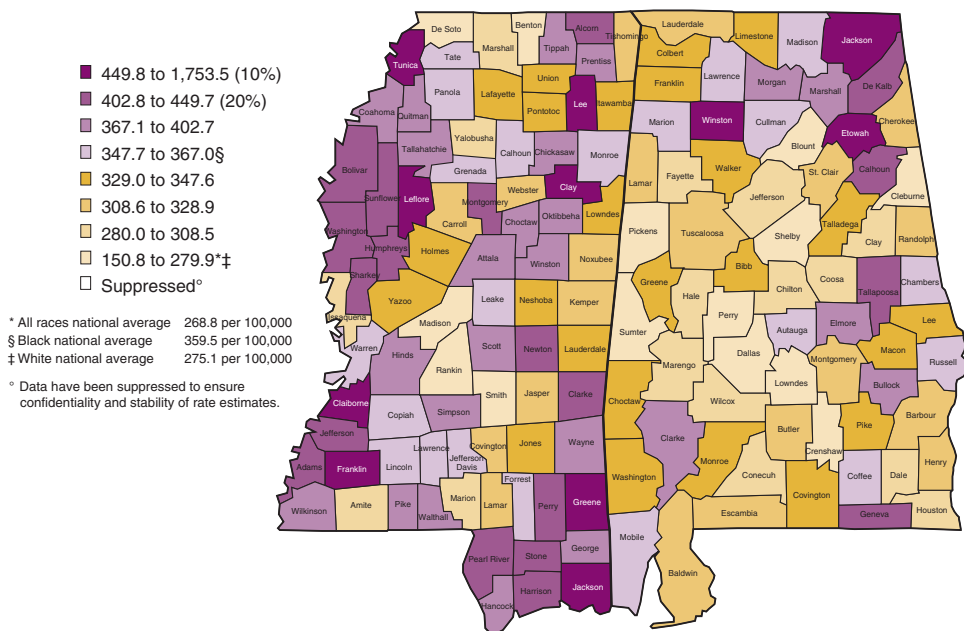


Maps prepared from data provided by: Surveillance, Epidemiology, and End Results (SEER) Program (www.seer.cancer.gov) SEER*Stat Database: Mortality–All COD, Public-Use With County, Total U.S. (1969–1999), National Cancer Institute, DCCPS, Surveillance Research Program. Cancer Statistics Branch. Underlying mortality data.

Map 6. Breast Cancer Mortality Rate: Black Female, 1969–1999 (Alabama and Mississippi)

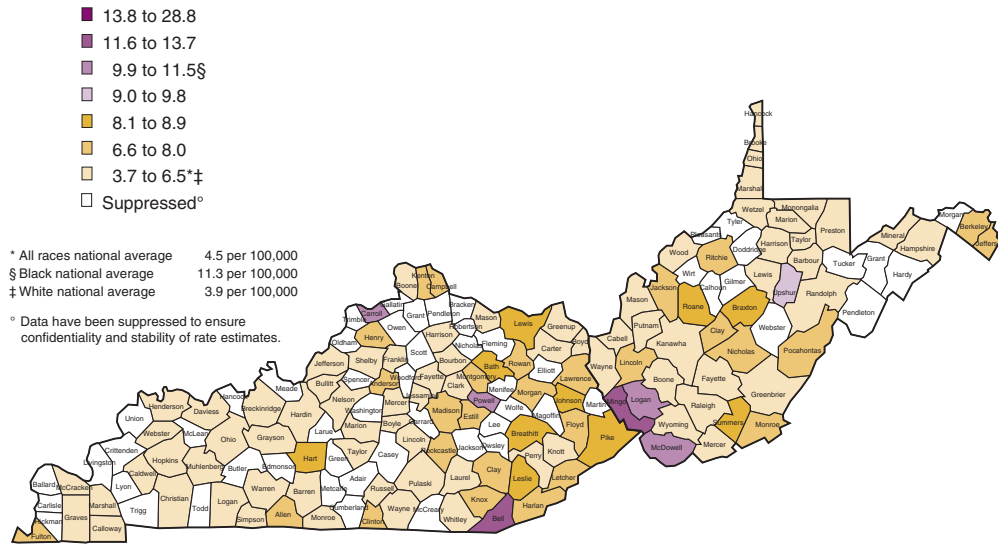


Map 7. Disease of the Heart Mortality Rate: Black Female, 1969–1999 (Alabama and Mississippi)

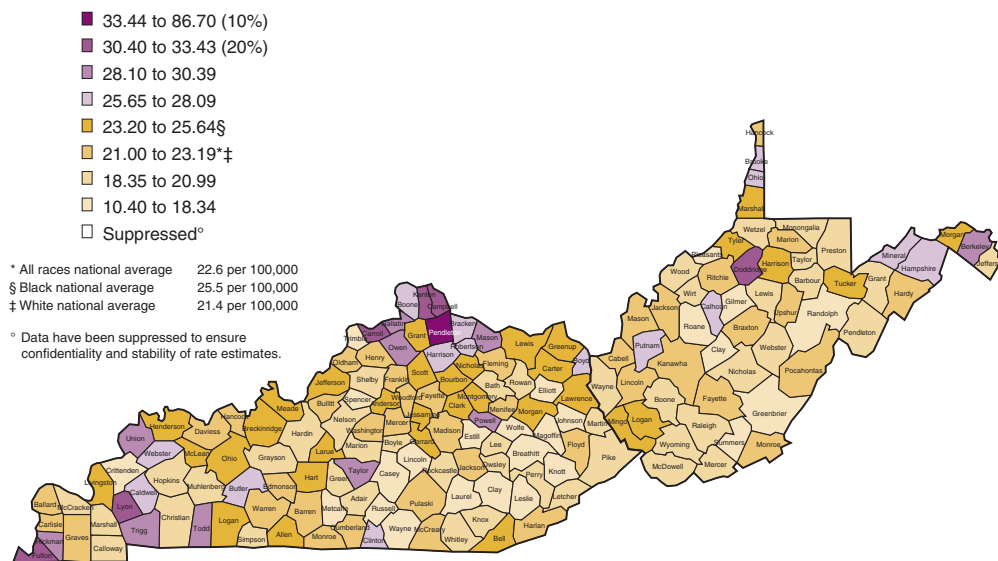


Maps prepared from data provided by: Surveillance, Epidemiology, and End Results (SEER) Program (www.seer.cancer.gov) SEER*Stat Database: Mortality–All COD, Public-Use With County, Total U.S. (1969–1999), National Cancer Institute, DCCPS, Surveillance Research Program. Cancer Statistics Branch. Underlying mortality data.

Map 8. Cervical Cancer Mortality Rate: White Female, 1969–1999 (Kentucky and West Virginia)

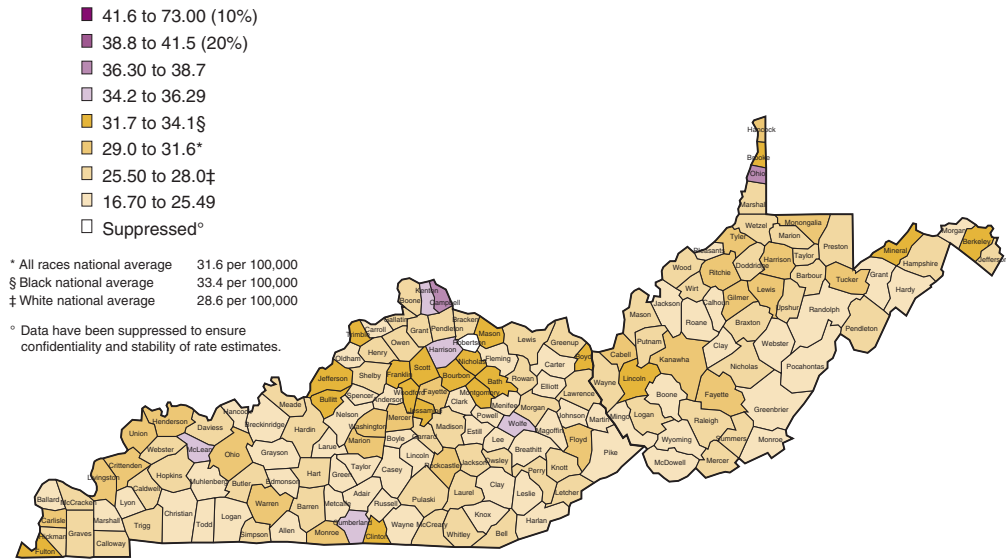


Map 9. Colon Cancer Mortality Rate: White Female, 1969–1999 (Kentucky and West Virginia)

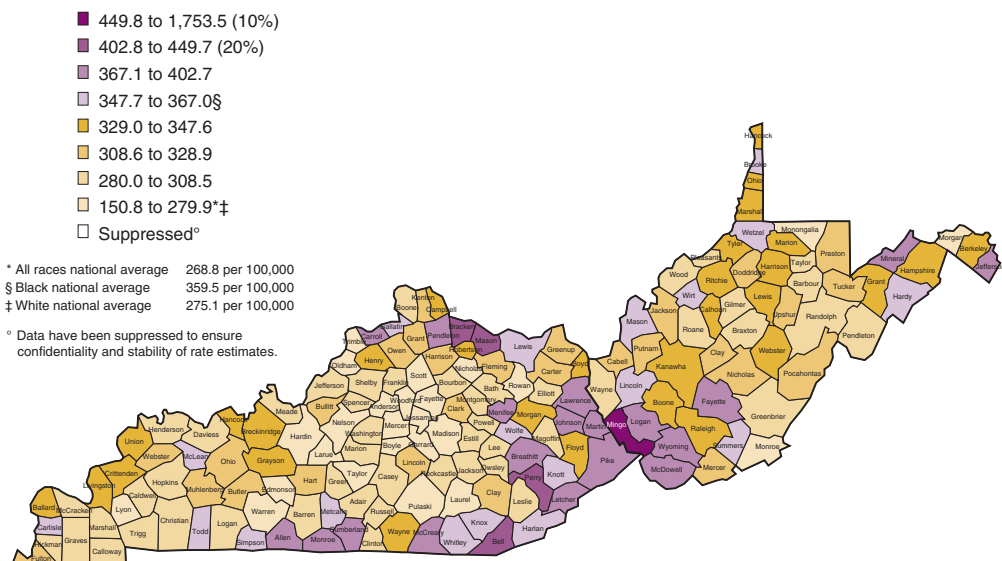


Maps prepared from data provided by: Surveillance, Epidemiology, and End Results (SEER) Program (www.seer.cancer.gov) SEER*Stat Database: Mortality–All COD, Public-Use With County, Total U.S. (1969–1999), National Cancer Institute, DCCPS, Surveillance Research Program. Cancer Statistics Branch. Underlying mortality data.

Map 10. Breast Cancer Mortality Rate: White Female, 1969–1999 (Kentucky and West Virginia)



Map 11. Disease of the Heart Mortality Rate: White Female, 1969–1999 (Kentucky and West Virginia)



Maps prepared from data provided by: Surveillance, Epidemiology, and End Results (SEER) Program (www.seer.cancer.gov) SEER*Stat Database: Mortality--All COD, Public-Use With County, Total U.S. (1969–1999), National Cancer Institute, DCCPS, Surveillance Research Program. Cancer Statistics Branch. Underlying mortality data.

Human Papillomavirus (HPV)

Sexually transmitted HPV infection is believed to be responsible for 90 to 95 percent of all cervical cancers. The risk of contracting HPV is influenced by a number of factors, including age, lifetime number of sexual partners, number of recent sexual partners, early age at first sexual contact, and race/ethnicity.¹⁹ Many HPV infections regress spontaneously. Research suggests that persistent infections are the most critical for later development of cervical cancer. Of the more than four dozen strains of HPV, 15 types appear to be most strongly implicated in cervical cancer, but it is not clear that these differences are important to mortality. HPV-16 accounts for about 50 percent of all cervical cancers. HPV types 18, 31, 33, and 44 together account for an estimated 20 percent.²⁰ A recent study suggests that 13 percent of the U.S. population aged 12 to 59 years may have serum antibodies to HPV-16, demonstrating exposure and infection. In addition, women are more than twice as likely as men to have antibodies to the virus (17.9 percent versus 7.9 percent).²¹

However, the existence of HPV does not predict cervical cancer. A recent international study suggests an association between the number of full-term pregnancies and increased risk of squamous cell cervical cancer among HPV-positive women.²² A second study using the same data indicates that HPV infection together with oral contraceptive use for five or more years significantly increases cervical cancer risk, but no increased risk was found for HPV-free oral contraceptive users.²³

At this time, HPV testing is not part of routine gynecologic examination, and current surveillance systems do not collect data on geographic variations in persistent HPV infection that would make it possible to study the relationship between geographic variations in HPV infection and variations in cervical cancer incidence.

A combined Pap/HPV screening test recently was approved by the Food and Drug Administration (FDA) as a primary screen for cervical cancer and its precursors in women aged 30 and older, and as a followup to any abnormal Pap test result.^{24,25} The sensitivity of HPV testing, particularly in conjunction with cytology, has been confirmed in studies^{26,27} conducted through the NCI-funded ASCUS/LSIL Triage Study (ALTS), which is comparing alternative strategies for initial management of mildly abnormal Pap test results.

However, the U.S. Preventive Service Task Force (USPSTF) concludes that “the evidence is insufficient to recommend for or against the routine use of HPV testing as a primary screening test for cervical cancer.” The USPSTF found poor evidence to determine the benefits and potential harms of HPV screening as an adjunct or alternative to regular Pap test screening.²⁸

Screening Rates

Since 1987, screening rates for all age and ethnic groups have been increasing,²⁹ but screening rates remain higher among urban women compared with those living in rural areas³⁰ and among younger women compared with older women.³¹ As Table 3 indicates, screening rates also vary by racial/ethnic group and by level of educational attainment.

Table 3. Screening Rates by Population Characteristic, Women 18 and Older, U.S. 2000

Race/Ethnicity	Rate
White (non-Hispanic)	82
Black (non-Hispanic)	84
Hispanic	77
American Indian/Alaska Native	77
Asian/Pacific Islander	67
Education (years, women 25 and older)	
11 or fewer	74
12	81
13 or more	86

Source: 2000 National Health Interview Survey data, NCHS, CDC, July 2002.

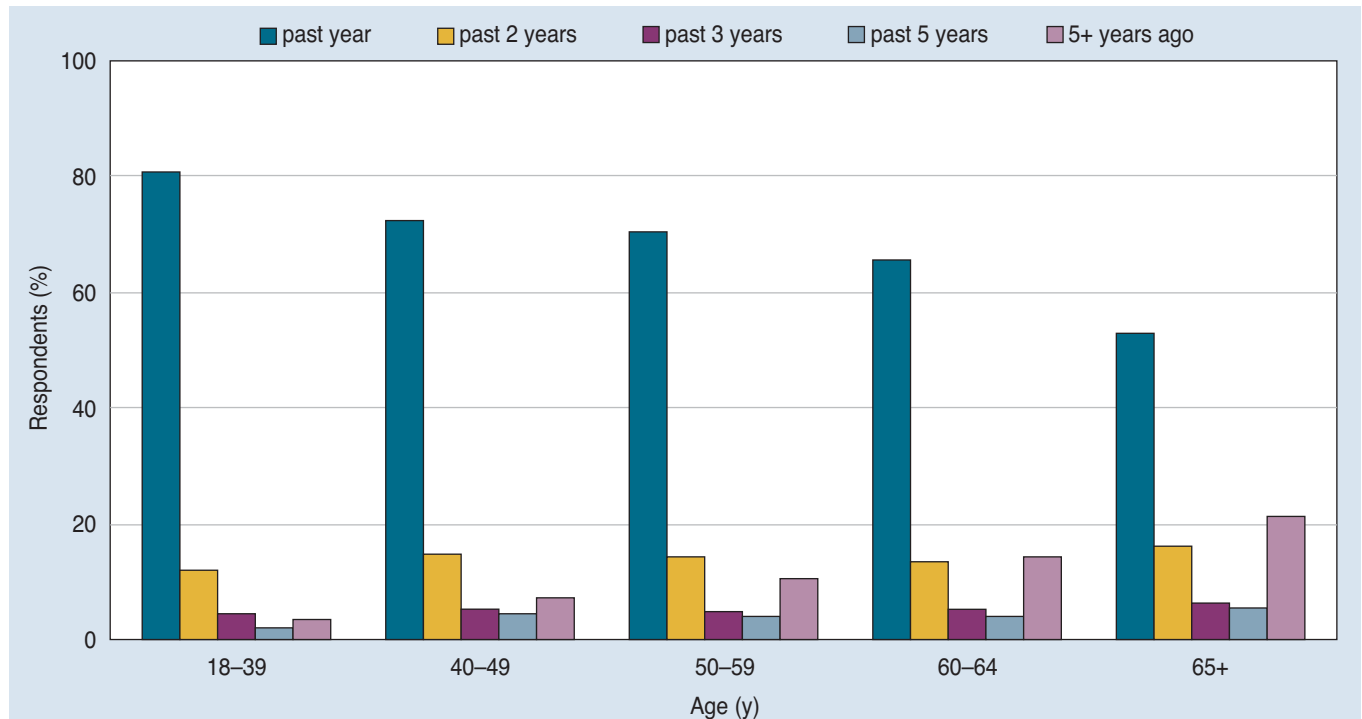
Retrospective reviews of the screening histories of women diagnosed with cervical cancer suggest that 50 to 70 percent of women developing invasive cervical cancer either did not have a Pap test within the five years prior to diagnosis or had never been screened.^{32,33} BRFSS data (2002) indicated that, nationally, more than 85 percent of women had received a Pap test within the previous three years,³⁴ though screening rates were higher among younger women and lower among older women (Figure 1). Factors that may contribute to lower rates among older women are related to less frequent

contact with gynecologists after the childbearing years and/or after tubal ligation or hysterectomy. Such lower rates may be appropriate in older women who have had hysterectomies and several subsequent negative Pap tests. Indeed, while the USPSTF strongly recommends screening for cervical cancer in women who have been sexually active and have a cervix, it recommends against routinely screening women older than age 65 for cervical cancer if they have been recently screened, the findings were normal with Pap tests, and the women are not otherwise at high risk for cervical cancer.³⁵ Lower rates may also be related to the failure of providers to recommend or perform the test on many older women as part of their primary care, particularly when the patient has comorbidities such as hypertension or diabetes that are perceived to pose a more immediate health threat.³⁶

A special analysis of BRFSS data (1995–1999) conducted by CDC staff for the Roundtable and the Think Tanks also indicates that, among white women, those who are Hispanic, older, less educated, and living in high mortality counties have the lowest screening prevalence. Among black women, the only discernable difference, due to small sample size, is lower screening rates among those aged 40–64 years. Data available at the time of the Roundtable and Think Tanks were too sparse to conduct similar analyses of Asian, Native American, or other groups.

NHIS data (1990–1999) show that Pap test use declines with age (while cervical cancer incidence and mortality risk increase with age). In addition, these data indicate that women

Figure 1. Percentage of Women Responding to the Question: “How Long Has It Been Since Your Last Pap Smear?” by Age Group



Source: Behavioral Risk Factor Surveillance System, 2002; survey data, Centers for Disease Control and Prevention, access at: <http://www.cdc.gov/brfss/index.htm>.

with less education, less income, those uninsured, and those without a usual source of care are less likely to be screened. However, other studies^{37,38} also indicated that a substantial percentage of women in managed-care plans who developed cervical cancer had not been screened in the three years prior to diagnosis. Conversely, there also appear to be populations of women who may be getting screened more often than necessary (e.g., those with consistently negative Pap tests who continue to be screened annually). Screening rates also are affected by cultural factors (e.g., modesty, fatalism, prohibitions against examination by male health care providers) and competing life priorities (i.e., screening may not be perceived as

important compared to income generation and fulfilling work and family responsibilities).

Several meta-analyses indicate that patient-oriented interventions such as reminder letters, patient education, and financial incentives^{39,40,41} can be effective in increasing Pap test screening and followup after abnormal test results.⁴² These interventions have been especially successful in increasing Pap test use among historically underserved women.⁴³ Likewise, provider-oriented interventions, including reminders and education, can increase screening rates.⁴⁴ Provider interventions such as these are particularly important since primary care providers have reported not notifying patients

of normal screening results⁴⁵ and sometimes failing to notify patients about abnormal findings.⁴⁶

Other Cervical Cancer Risk Factors

Smoking has been identified as a contributing cause of cervical cancer.⁴⁷ In addition, HIV-positive women are at increased risk for cervical intraepithelial neoplasia (CIN) and cervical cancer, which tend to be more progressive and aggressive in these women.⁴⁸ The CDC lists cervical cancer as an AIDS-defining condition.⁴⁹

Diagnosis and Treatment Patterns

Available studies on diagnosis and treatment patterns for cervical cancer do not paint a clear picture of this aspect of care, particularly with regard to insurance status. Not surprisingly, data from ACoS-accredited hospitals, which tend to serve more affluent and better-educated populations,⁵⁰ suggest that lower-income women are more likely than higher-income women to be diagnosed at a later stage of disease. Uninsured women are more likely to be diagnosed with late-stage cervical cancer than those with private insurance.⁵¹ Women in Medicare managed-care plans and HMO enrollees under age 65 tend to be diagnosed at earlier stages of disease than are women in traditional fee-for-service (FFS) plans.^{52,53}

Limited state-level data provide additional information. For example, research in Michigan linking Medicaid, cancer registry, and death certificate data⁵⁴ in that state indicate that about the same percentage of women in Medicaid HMO/managed-care and fee-for-service plans are

diagnosed at early stages, but, as in other populations, later-stage diagnosis increases with age. Notably, older Medicaid patients in long-term care facilities are more likely to be diagnosed at later stages than women not in institutionalized settings. It is unclear what portion of this problem reflects comorbidities versus the place of residence. The Michigan research also suggests that poor patients with no health coverage prior to diagnosis and subsequent Medicaid coverage, and those without continuous coverage of any kind, are more likely to be diagnosed at later stages and die.

The ACoS data indicate that black women are more likely than white women to receive no treatment after a diagnosis of cervical cancer, regardless of disease stage. The differences detected in this sample are likely to be magnified in rural and other medically underserved and poor populations. AHA data include non-ACoS hospitals; these hospitals are more likely to be smaller and have fewer full-time medical personnel. They more often are located in rural counties with low income and educational attainment, and in counties with higher cervical cancer mortality. They also are less likely to have oncology and radiation services. Eighteen percent of all U.S. counties have no hospital, and cervical cancer mortality is markedly higher in these counties compared to those with hospitals.

SEER data for 1992–1997 indicate that patients with stage I disease (more than half of all cases), particularly those under age 50, are more likely to be treated with surgery alone than are older women, who are more likely to

be treated with surgery plus radiation. Women with more advanced disease are most likely to be treated with radiation as the primary modality.⁵⁵ Adding chemotherapy to the treatment regimen lengthens survival but provides only modest reductions in mortality. A small population of women exists who are diagnosed but whose disease appears to be unstaged and untreated. Data on this population show no significant differences in treatment by race, income, or educational level at any disease stage. Overall, 5 percent of patients do not receive treatment, but up to 20 percent of women over age 65 with stage II–IV disease are receiving no treatment.⁵⁶

Identified Needs and Strategies to Reduce Cervical Cancer Mortality And Improve Women’s Health

CCMP participants identified four major areas of emphasis in which policy changes and interventions at Federal, state, and local levels could significantly impact women’s health and reduce cervical cancer mortality, particularly in high mortality geographic areas:

- Access, including services, outreach, and navigation
- Information and communication
- Collaborations, partnerships, and advocacy
- Research

To reduce excess cervical cancer mortality, it is essential to understand the diverse cultures and risk factors of affected populations and the

barriers to care they face. Populations in the geographic areas with highest cervical cancer mortality are quite heterogeneous, even within major racial/ethnic groups. Further, factors that appear to be patient group characteristics may in fact be system or infrastructure characteristics. However, some characteristics are shared by most women at high risk of cervical cancer mortality: poverty, lack of insurance, distance from health care, modesty (particularly among older women), fatalism concerning cancer, patriarchal cultures, a distrust of government and mainstream medicine, and a resilience that enables these populations to survive under harsh living conditions.

Access—Outreach, Services, and Navigation

Access includes both financial and physical access to necessary services as well as outreach and navigation services that enable access. CCMP participants identified seven (7) high-priority issues that address access to quality health care:

1. Enabling Patients to Have a “Medical Home”

Data from the 2000 National Health Interview Survey⁵⁷ show that the greatest disparities in Pap test use (during the previous three years), defined as differences between the highest and lowest groups for all age groups combined, were associated with having or not having a usual source of care (26 percentage point difference), age (a significant downward gradient with increasing age), and immigration within the past 10 years compared with U.S.-born or less recently immigrated women. Disparities also

were observed by level of education, family income, chronic disability, race, and ethnicity, but these differences were not as great as those due to health care access, age, and immigration.

CCMP participants emphasized strongly the need for women at risk for cervical cancer, other cancers, and other chronic conditions to have a “medical home”—a usual source of medical care where the patient can receive screening and counseling, experience continuity of care, and develop trusting relationships with the medical staff. The medical home also can serve as a hub with linkages to other community services.

Among the suggestions for improving access to health services were:

- Leveraging resources by adding cervical health and other screening services to the services offered at existing clinics, health centers, or other provider sites.
- Building necessary infrastructure where it does not yet exist.
- Basing resource distribution and redistribution on small-area analyses of areas of greatest need.
- Encouraging state health departments to take the lead in efforts to improve services for high-risk populations.

CCMP participants suggested that access issues in high mortality regions may have more to do with inadequate primary, tertiary, and support service infrastructure and problems

linking primary care clinics to the hospital system than factors such as race or ethnicity.

Primary health services available in regions experiencing high rates of cervical cancer and other disease mortality offer the possibility of coordination of a more extensive range of social and medical services. These include Health Resources and Services Administration (HRSA)-funded health centers, which include community health centers (CHCs), migrant health centers, homeless health centers, and public housing primary care centers.⁵⁸ For more than 30 years, HRSA-funded centers have been a safety net for underserved communities, providing primary health care for some of the nation’s most vulnerable populations. These centers also receive a substantial portion of their revenues from the Centers for Medicare and Medicaid Services (CMS) through Medicaid funding.

Approximately 40 percent of CHC patients are uninsured, and almost 90 percent are low income. More than two-thirds of patients have incomes below the poverty level. More than 10 million people receive medical services at almost 4,000 sites. In some communities, CHCs are the predominant source of care.⁵⁹

In addition to the network of HRSA-funded centers, a patchwork of approximately 3,300 rural health providers serves many of the underserved women in areas of high cancer mortality. Many of these rural health providers are private practices, clinics within rural hospitals, or small part-time clinics in remote

areas. Those certified as rural health centers by CMS receive reimbursements from Medicaid and Medicare that include an added reimbursement factor to help them remain viable in their locations. Because of financial pressures, however, the number of these rural health centers is declining in many areas, including Appalachia. To maintain and better integrate health services in rural areas, it will be important to include this group of providers. Though the rural providers are not obligated to participate in a demonstration project or other initiative to establish an integrated rural health system, they may be able to play a role in cervical cancer education and counseling. A sampling of the range of types of services that could be organized to play a role in cervical cancer education and counseling. is presented in the following paragraphs.

Other nonfederally funded health centers exist that are structurally similar to HRSA centers. Like HRSA and Indian Health Service (IHS) or tribally operated primary care centers, many have been designated Federally Qualified Health Centers (FQHCs) and, as such, receive cost-based reimbursements from Medicaid and Medicare.⁶⁰ As in federally funded programs, the percentage of patients who are enrolled in Medicaid managed-care plans has increased in recent years.

In some locations, state and county health department facilities and private primary care practices also provide primary care. States and counties may provide categorical maternal and child health care, immunizations, STD (sexually transmitted disease) treatment, or other targeted

programs through Federal or other grants. Some patients who have no primary care facility in their local area or who choose not to seek care at available clinics may rely on emergency rooms for their primary care needs.

In a project currently under way in Texas and funded by the Robert Wood Johnson Foundation, researchers are attempting to link medical and community services to provide a medical home with culturally responsive health care for women at high risk for cervical cancer who do not have a physician or health insurance. Representatives from area primary and specialty care facilities, public housing health service programs, other system components, academia, and the business community are participating on the project steering committee.

2. Eliminating the Disconnects Between Primary Care, Screening Services, and Followup/Treatment at Hospitals

Linkages between HRSA primary care centers and area freestanding screening and hospital services often are tenuous. Similarly weak connections, if any, occur between other primary care providers and local hospitals in areas with high cervical cancer mortality. Moreover, these services may be geographically distant from each other and from patients living in rural areas. As a result, established procedures for rapidly referring women who have abnormal Pap tests may not be in place. In such situations, women may become lost in or drop out of the system and not receive the diagnostic, follow-up, or treatment services they

need. In addition, it is sometimes unclear whether the primary care center or an oncologist should manage the care of women with advanced cervical cancer.

Currently 50 states, 4 U.S. territories, 13 American Indian/Alaska Native organizations, and the District of Columbia have elected to participate in the Breast and Cervical Cancer Mortality Prevention Act of 1990.⁶¹ In 2000, Congress passed the Breast and Cervical Cancer Treatment and Prevention Act to help make treatment services more accessible to women enrolled in the National Breast and Cervical Cancer Early Detection Program (NBCCEDP). As of January 1, 2005, 49 states and the District of Columbia have received approved Medicaid amendments to participate in this program. Under it, states extend Medicaid coverage to women whose cervical abnormality is detected through the CDC's NBCCEDP. The Federal medical assistance percentage (FMAP) rate covers 65 to 85 percent of the cost of treatment, with state Medicaid dollars covering the remainder. While an important step in linking screening with care, the early detection program covers only 12 to 15 percent of eligible women (usually women with family incomes 250 percent or less of the Federal poverty threshold).⁶²

Disconnects between primary care, screening, and treatment often are compounded by transportation/distance from care, payment and childcare issues, and lack of understanding by patients of the need to pursue follow-up care in the event of an abnormal Pap test. Difficulty in navigating the health system appears to be a major barrier. Eliminating these disconnects for

both physicians and patients was seen as a crucial step in improving care for women with cervical abnormalities and other health conditions for which continuity of care is essential. The need to coordinate federally funded medical and social services in rural areas was emphasized repeatedly.

The HRSA, NCI, and CDC pilot Health Disparities Collaboratives are addressing many of these issues in a pilot project being conducted in several HRSA centers. Among the goals of this project is a plan to perform Pap tests on 90 percent of female primary care patients, with test result notification within 30 days. Follow-up colposcopy is provided for women needing further evaluation; the program seeks to perform at least 80 percent of necessary follow-up procedures within 90 days. For women diagnosed with early cervical cancer, the goal is to have treatment begin within 90 days of diagnosis. The program is being documented and evaluated to determine if it can be expanded to the entire network of HRSA primary care clinics. A description of these cancer health disparities collaboratives can be found at the Web site: <http://healthdisparities.net>.

3. Reaching Women Who Have Rarely or Never Been Screened for Cervical Cancer and Other Diseases

To reduce cervical cancer mortality, it is critical to reach rarely or never screened women, since half of all invasive cervical cancer cases are found in women either who have not received a Pap test in the previous five years or who have never had a Pap test.^{63,64}

The CDC NBCCEDP was an important step in attempting to reach more low-income women with breast and cervical cancer screening, particularly those in rural areas. On average, however, the NBCCEDP sites reach only 15 percent of eligible low-income women, and it appears that some programs may be screening some women more frequently than is necessary. ACS and USPSTF guidelines recommend Pap tests every three years for women with previous normal test results; the NBCCEDP screens all women annually. Some CDC program sites have been more successful in reaching eligible women than others. CDC is conducting evaluations to determine why these programs are succeeding and how contributing procedures, activities, and other factors can be incorporated to strengthen performance at other program sites.

Greater numbers of outreach workers are needed, both in the CDC screening programs and in other community health programs, to locate rarely or never-screened women and facilitate their entry into screening programs. Outreach workers are particularly needed in rural areas, especially in counties with limited or no county health services. Such workers, typically members of the community who receive training to fulfill this role, are sometimes referred to as lay educators, community health advisors, community health representatives, *promotoras*, navigators, or by other titles. They are key players in attracting high-risk women into the health care system through culturally appropriate education, lay counseling, and other interventions. These workers also may arrange medical appointments, accompany women to

screening and follow-up appointments, and help with transportation and childcare needs.

CCMP participants suggested that outreach and screening be expanded to include emergency rooms, other providers of women's health services, and work sites. To the extent possible, the number of mobile units providing screening, follow-up, and at least limited treatment services should be increased. In addition, screening services should be made available in the evening and on weekends. Free screening could be provided to groups with limited health care access, such as migrant health workers and the poor. CCMP participants reported that, for example, a pilot program in Santa Clara County, CA, is reaching out through media and other communication channels to hard-to-reach Asian women, many of whom are relatively recent immigrants, to provide Pap tests at a free clinic. The screening program also is proving successful as a way to draw women into the system for the care of other health problems. However, when cancer is diagnosed, unless a woman is Medicaid eligible, the program currently faces the same lack of referral resources as HRSA clinics.

In another pilot effort reported by the CCMP participants, NCI, CDC, the American Cancer Society, the Centers for Medicare and Medicaid Services (CMS), and the Department of Agriculture Extension Service are testing the benefit of using Extension Service workers to reach rural women in eight states with evidence-based breast and cervical cancer screening promotion program materials.

Some of the actions proposed by CCMP participants may require supportive policy, modified programs, and funding. For example, they recommended that lay health workers, many of whom are volunteers, should be paid, particularly when they are fulfilling a role the physician is unable to undertake due to time constraints. Moreover, to sustain the effort, such workers should become part of an institution's economic infrastructure rather than being supported by grant funding. CMS representatives indicated that Medicaid currently can provide matching funds for community health advisors if the state requests a Section 1115 waiver. Section 1115 of the Social Security Act permits authorization of experimental, pilot, or demonstration projects that the Secretary, HHS, deems likely to assist in promoting the objectives of the Medicaid statute.⁶⁵

Medicaid also provides funding through disease management organizations (DMOs) that could provide an option for supporting this type of staffing within a system demonstration project in a specific community. While cancer currently is not one of the diseases specified for this type of funding, it was suggested that NCI work with CMS leadership to include cancer in the categories of disease supported via this mechanism.

Some CCMP participants, however, maintained that further research is needed to confirm the efficacy of the community health advisor role.

In addition, the recently revised cervical cancer screening guidelines⁶⁶ may enable

NBCCEDP and other program resources to be redirected to outreach activities and staffing. The American Cancer Society recommends:

1. Cervical cancer screening should begin approximately three years after a woman begins having vaginal intercourse or no later than by the time she is 21 years of age.
2. Cervical screening should be done annually with regular Pap tests or every two years using liquid-based tests. At or after age 30, women who have had three normal test results in a row may get screened every two to three years. But the doctor may suggest getting the test more often if a woman has certain risk factors such as HIV infection, a weak immune system, or multiple partners.
3. Women 70 years of age and older who have had three or more normal Pap tests and no abnormal Pap tests in the last 10 years may choose to stop cervical cancer screening.
4. Screening after total hysterectomy (with removal of the cervix) is not necessary unless the surgery was done as a treatment for cervical cancer or precancer. Women who have had a hysterectomy without removal of the cervix should continue cervical cancer screening at least until age 70.

Primary care physicians and other providers also play a vital role in reaching rarely or never-screened women. These providers need to be encouraged to ask women patients about screening history, provide cancer education, and perform screening when indicated on women who have come in for other reasons. For this strategy to be successful, particularly with

providers who must see 50 to 60 patients daily, reimbursement would have to be available for such “opportunistic” screening (see also Improving Coverage and Reimbursements, on page 24).

4. Providing Patient Navigators to Help Women Through the Health System Once an Abnormality Has Been Detected

Some women who are screened and found to have an abnormality never receive follow-up diagnostic and treatment services because they are fearful or ashamed of a possible diagnosis, have no telephone or fixed address (e.g., homeless or migrant women), or do not understand the meaning of the test result and the need for additional care. Some patients do not follow up on abnormal test results because they lack transportation or child care needed to attend medical appointments. For all of these reasons, culturally competent patient navigators or case managers are needed to ensure that women enter the health system and receive the guidance and assistance needed to receive necessary treatment.

Patient navigators typically assist women with scheduling and keeping appointments; explain medical terminology and the importance of treatment; and help women obtain financial, medical, transportation, child care, and other assistance they may need. It is essential that navigators be highly knowledgeable about the local health and supportive care systems and resources to fulfill this role. A number of such programs, tailored to local needs, already are under way or planned in communities across the country. One such

program now operating in nine sites (though not limited to cervical cancer) is sponsored by CRCHD. <http://healthdisparities.net>.

The need for navigators was considered a high priority by CCMP participants. Funding to support them could come from Federal, state, or local sources. A representative from CMS indicated that Medicaid can pay for case management (patient navigator) services through the 1115 waiver mechanism as well as in conjunction with “hybrid” proposals for expanded Medicaid coverage.

For patient navigators to be optimally effective, an infrastructure needs to be in place. Physicians must be up to date on screening and treatment guidelines, and patient reminder and tracking systems must be in place to ensure that patients are offered information and receive all of the services needed in a timely manner. Similarly, patient navigator programs should include an evaluation component to ensure that the program is effective. As with Community Health Advisors, further research on the costs and benefits of patient navigator programs was urged.

5. Increasing the Number of Providers of the Patient’s Gender/Race/Ethnicity

Modesty, distrust, and cultural taboos may cause women in high cervical cancer mortality areas to avoid screening and follow-up care if only male physicians are available to conduct the examination. Increasing the number of female providers, particularly providers of the patient’s race/ethnicity, is an essential step in breaking down resistance to screening and saving

women's lives. African Americans, Hispanics/Latinos, and Native Americans together account for approximately 21 percent of the U.S. population, but only 8.6 percent of physicians.⁶⁷ The proportion of women physicians in these groups is even lower. While increasing the number of women physicians from these racial-ethnic groups is an important long-term strategy, CCMP participants also urged the training of nurses and other health care providers to perform Pap tests and colposcopy. Women in the above-listed racial-ethnic groups are much better represented among nurses and other types of providers, making this a more feasible short-term strategy. National support to achieve this objective could include national training programs and scholarships, National Health Service Corps (NHSC) placements, and provider incentives.

6. Improving Coverage and Reimbursements

Coverage and reimbursement issues permeated the discussions of access to cervical cancer screening and treatment. Physicians are reducing the number of new Medicare and Medicaid patients they accept because of low reimbursements, and reduced reimbursement rates are straining the budgets of publicly funded health centers that count on Medicare and Medicaid programs for major portions of total patient care revenues. Reimbursement is needed to specifically encourage primary care and other providers to ask about Pap screening history, provide cervical cancer education, and perform screening when indicated on women who have come in for other reasons. Unfortunately, categorical funding grants often

constrain providers' ability to provide multiple services during a single medical encounter.

CCMP participants assigned a high priority to the suggestion that over a 10-year period, the CDC National Breast and Cervical Cancer Early Detection Program and Treatment Act should be fully funded to provide 100 percent coverage of eligible women, including patient navigator services. In addition, it was recommended that Medicaid or Medicare coverage for at least one year should be provided to any uninsured or underinsured woman (living in poverty) with cervical cancer whose disease was not detected through the NBCCEDP.

According to a CMS representative, a woman who receives cancer treatment through Medicaid remains eligible for necessary follow-up care and additional treatment as long as she has no other insurance coverage, is under age 65, and continues to require treatment. If a patient reaches age 65 after her initial course of treatment is complete, she will be dropped from the Medicaid rolls. Older women who are not eligible for Medicare (e.g., recent immigrants) but later need additional treatment currently must find another source of payment.

Paperwork related to federally funded programs should be easy to read and complete, and be streamlined to encourage provider participation. Recent legislation⁶⁸ includes a provision to help increase and equalize reimbursements between urban and rural areas. This, however, may not be sufficient to overcome rural payment issues.

7. Improving Telemedicine and Multidisciplinary Consultations

Multidisciplinary consultation prior to cancer treatment selection is considered a key element in optimal cancer care, but this option currently is unavailable to most women in high cervical cancer mortality areas. Telemedicine may provide a means of bringing review of diagnostic test results and treatment recommendations to areas without cancer specialists. CMS currently provides reimbursement for these services.

Information and Communication

Current efforts at information dissemination and communication about cervical cancer risk, screening, and treatment are not reaching high-risk populations effectively. Possible strategies in seven (7) key areas have potential to improve information outreach both to patients and to health professionals:

1. Improving Awareness and Knowledge Levels About Cervical, Breast, Colorectal Cancer and Other Screenable/Treatable Disease Mortality

The Institute of Medicine (IOM) has underscored the need for patient education programs to increase patients' knowledge of how to access care and participate in treatment decisions.⁶⁹ A second Institute report in 2003⁷⁰ reiterated the need for public and private organizations to work to improve the public's understanding of cancer prevention and early detection and their importance for reducing cancer mortality. CCMP participants suggested that public and private agencies develop and

implement a cervical cancer awareness and education media campaign that would be funded nationally but implemented regionally so that it could be tailored to high-risk populations and geographic areas. In addition to providing information about cervical cancer, its prevention and treatment, and available services, a key focus of these campaigns would be to raise public awareness of the longstanding disparities in cervical cancer mortality and to motivate action.

2. Developing and Providing Linguistically and Culturally Appropriate Information

The Federal Government established standards for Culturally and Linguistically Appropriate Services (CLAS) in health care in recognition of the impact of limited English proficiency and linguistic isolation on health disparities. The proportion of linguistically isolated households (i.e., in which no person over 14 years old in the household can communicate in English) remained at approximately 5 percent of all U.S. households for the past decade. However, in addition to the traditional destination states of many immigrants (e.g., California, Texas, New York), some states have seen dramatic increases in this population (e.g., 10 percent of Asian households in Kentucky, 18.6 percent of Spanish-speaking households in North Carolina).⁷¹

It is therefore essential to address both health literacy and overall literacy issues that affect communication with populations at high risk of death from cervical cancer, including both native- and foreign-born individuals.

Native-born populations in high cervical cancer mortality areas tend to have limited educational attainment and require materials written at a level that matches their reading levels. For Asian, Hispanic/Latina, and other immigrant populations with high rates of cervical cancer incidence and mortality, materials must address not only limited or complete lack of literacy in English but also, in many cases, limited literacy in their native language. Low literacy among women of all races and ethnicities has been shown to be directly linked to lower cervical cancer screening knowledge.⁷² Materials designed for visual learners (e.g., pictographs) and the oral transfer of information (e.g., videos, story telling, talking circles) are needed to reach women at all levels of literacy with essential information on cervical cancer prevention and treatment. Few such materials are available and more need to be developed.

Educational materials must be both understandable and culturally appropriate. The continuing inflow of immigrants from numerous countries, the diverse cultures that exist even among immigrants from the same nation, and the regional cultural differences among native-born women create a massive challenge to meeting their information needs. Experience with Native American populations, for example, indicates that materials developed locally or regionally for specific populations often are the most effective, but this approach is costly and time consuming. Regional efforts can, however, be supported at the national level. The Native CIRCLE (Cancer Information Resources Center and Learning Exchange) program, cosponsored by NCI and the Mayo

Comprehensive Cancer Center, stimulates local development of cancer education materials for diverse Native American and Alaska Native audiences. It has developed materials with Native American themes that have proven useful for a number of tribes or have been adapted to reflect specific Native cultures (<http://mayoresearch.mayo.edu/mayo/research/cancercenter/native.cfm>). Similarly, an NCI-supported study demonstrated that culturally and linguistically tailored educational materials increased cervical cancer screening among Chinese American women in Seattle.⁷³ Evaluation of these programs is ongoing to determine their efficacy in reaching specific groups of women.

Translation needs are another critical component of information services for women at high risk of cervical cancer mortality. Literal translations often do not increase the readability and comprehension levels. Among others, the IOM⁷⁴ has noted that unaddressed language barriers can affect the delivery of adequate health care due to poor information exchange, misunderstanding of physician instructions, inadequate shared decision-making, loss of important cultural information, or ethical compromises. In addition, language barriers can negatively affect adherence to medication regimes, appointment attendance, and patient satisfaction. However, due to the lack of translators in the variety of languages required, particularly translators who are sufficiently familiar with medical terminology to translate information about treatments and procedures with accuracy, health care providers in many areas must rely on family members, including

children, or persons who are strangers to the patient to provide translation services.

Innovative approaches to developing interpreter networks tailored to the populations in a given geographic location are sorely needed. NCI recently has begun a shift from translation of cancer education materials to “trans-creation,” which often renders a different but more culturally appropriate framing of information.

Of note, the California legislature *passed* SB 853, Culturally and Linguistically Appropriate Services Bill, in 2003.⁷⁵ This bill requires the Department of Managed Health Care to adopt, not later than January 1, 2006, regulations establishing standards and requirements to provide health care service plan enrollees with access to language assistance in obtaining health care services. The regulations would require standard and specialized health care service plans to implement programs to assess enrollee needs, to provide translation and interpretation for medical services and translation of vital documents to enrollees, and to report to the Department regarding internal policies and procedures related to cultural appropriateness. The bill requires the regulations to determine that a health care service plan is compliant with requirements if it meets the same or similar standards imposed by the Medi-Cal program.

Opponents of the bill fear that interpreter costs could exceed provider reimbursements under the state’s Medicaid plan, causing physicians to cease providing services to this

largely underserved population. However, according to one review of funding options for language services and examples from the field,⁷⁶ all states can obtain a 50 percent Federal match for language services provided to Medicaid and State Child Health Insurance Program (SCHIP) recipients, or a greater percentage if language assistance is adopted as a covered service under the state health plan.

3. Enhancing Health Professional Education

The literature shows that systems, including reminder systems and patient tracking with feedback to physicians, are far more effective (than Continuing Medical Education [CME] or other educational or information) to ensure that physicians provide preventive services. Some evidence also suggests that systems can be set up to promote culturally appropriate care and that these are more effective than individual-based education efforts. Participants emphasized the need to educate practicing physicians and those still in training in the following high-priority areas: (1) encouraging physicians to review screening history and advise women, including Medicare beneficiaries, about screening at each medical encounter, (2) communicating the importance of Pap test screening to women seeking treatment for sexually transmitted diseases, and (3) ensuring culturally competent care in cervical cancer primary, secondary, and tertiary prevention and treatment. With regard to cultural competency, the American Medical Association has produced a video and accompanying workbook for use by physicians to sensitize them to the importance of

accommodating cultural differences when providing care.⁷⁷ In addition, a recent study suggests that physicians in health centers need assistance in recognizing and accommodating patients with limited literacy to ensure the transfer of cervical cancer-related information.⁷⁸

Participants cited the need for unambiguous and simply stated guidelines on cervical cancer screening, abnormal cytology, and treatment. Efforts are needed to improve providers' knowledge about screening and follow-up guidelines and about how to take advantage of opportunities to discuss screening when patients come in for other reasons. In California, for example, a short CME course targeting Vietnamese physicians was highly successful in raising their awareness and knowledge about cervical cancer and screening and follow-up guidelines. The Health Disparities Collaboratives are working to enhance provider knowledge in these areas and to coach health center providers on how best to provide these services to diverse populations. Training also is being provided on cultural competence, and retraining to accommodate staff turnover is being addressed. Further, providers are being trained to use a cancer registry system, the Patient Electronic Care System (PECS), that should assist them in monitoring patient progress.

Funding is needed for scholarships to increase the number of female and minority health providers, including physicians and other facilitators, serving underserved populations. Training funds also are needed for training community health advisors, case managers, and patient navigators.

4. Enhancing Provider-Patient Communication

Communication between patient and provider was identified as an area needing substantial improvement. For example, reminder systems are needed to help inform both patients and providers when screening and follow-up care is due. CHC and other programs currently are experimenting with different types of reminder systems.

The care model being implemented in the HRSA/NCI/CDC cancer control Health Disparities Collaborative pilot centers includes provider-patient shared decision-making. Under this model, the provider is to assess and ask the patient about her conviction to continue screening, identify barriers to screening, and inform the patient about screening and followup. The information is to be tailored to address identified barriers, and a written plan for screening and followup is to be provided to the patient before she leaves the provider's office. Tools to assist providers in this communication are being designed and tested. In addition, patients are to be given self-management worksheets that help them keep track of when they are due for screening and other care.

5. Using Lay Health Workers to Increase Population Awareness of the Importance of Screening

Volunteer and paid lay health workers are a crucial component of the cervical cancer education network. These workers, drawn from the community, have credibility and a trust relationship with patients that may take

physicians weeks or months to cultivate. Unlike most physicians, these workers also have the time to explain information in detail and to meet with target-population women in familiar settings including churches, health fairs, other community events, and women's homes.

Geographic areas with high cervical cancer mortality are populated primarily by marginalized populations with high rates of diabetes and other health problems. Educational program funding for these conditions is scarce; some participants felt that additional evidence may be needed to persuade local resource allocators to fund lay health worker programs targeting cervical cancer.

6. Providing a Central Resource for Cervical Cancer and Other Disease Information and Intervention Strategies

A national cervical cancer Web site was suggested that would link national organizations and their informational and other resources so that states and localities could easily obtain publications and materials. Native CIRCLE helps to disseminate cancer education materials for American Indian and Alaska Native populations but does not reach all populations with high cervical cancer mortality. NCI, in collaboration with CDC, the Substance Abuse and Mental Health Services Administration (SAMHSA), and the American Cancer Society (ACS), has launched Cancer Control PLANET (Plan, Link, Act, Network with Evidence-based Tools, <http://cancercontrolplanet.cancer.gov>) to assemble in one place information on evidence-based interventions and tools that can

be downloaded by provider organizations and used in or adapted to varied care settings. If this or a similar Web site were established as a clearinghouse to include cervical cancer control programs along with other evidence-based cancer control programs, targeted efforts would be needed to make state and local health administrative and provider organizations, voluntary and advocacy organizations, and the private provider network aware of this resource.

7. Improving Medical Records Maintenance and Retrieval Systems

Improved medical records maintenance and retrieval systems were cited as important for retaining patients in the health system, helping providers to rapidly access and review patients' medical information, and reducing cost by eliminating the need for repeat procedures. Critical to the success of using medical records to improve services is regular and compassionate feedback to physicians. As advances in information technology become more widely used by providers, monitoring of the impact of these technologies on health disparities will be needed.

Collaborations, Partnerships, and Advocacy

To reduce health system fragmentation, improve continuity and quality of care, and make the most efficient use of available resources, expanded, new, and innovative collaborations and partnerships are needed among national, regional, and local providers and other stakeholders. In addition, increased advocacy concerning cervical cancer is needed.

1. Establishing and Strengthening Partnerships That Promote a “Whole Woman” Approach to Care

It was proposed that all government programs, including non-DHHS agencies such as the Department of Veterans Affairs (VA), the Department of Defense (DoD) health system, and state and local programs with an interest in and resources devoted to women’s health establish partnerships to promote a “whole woman” approach to care, possibly as a national women’s health initiative through which services related to cervical cancer could be integrated. Such an approach dovetails with the expressed need for women who depend on publicly funded health programs to have a “medical home”—a usual source of comprehensive medical care.

Through grants, the DHHS Office of Women’s Health has established a number of Centers of Excellence that provide models for comprehensive women’s health services based both at community centers and at academic medical centers (<http://www.4woman.gov/owh/CCOE/>).

2. Providing and Sustaining Funding for Coalitions, Partnerships, and Community-Based Quality Services

The CHCs offer a logical starting point from which to build a system of comprehensive care for many of the women in areas with high cervical cancer mortality. Any such linked system of services must be adequately funded and tailored to the cultures and other characteristics of local populations.

In addition to its health centers, HRSA supports two mechanisms that have significant potential to facilitate health system partnerships. One of these, the community-controlled state primary care associations, provides a locus for contacting and collaborating with primary care resources in the state. The second, primary care offices, usually are housed within the state health department; their role is to try to bring together the diverse categorical and other programs at the state level to coordinate and improve primary care delivery for the underserved. Most do not have the leverage to resolve issues concerning flexibility in the use of categorical funds, but they can facilitate bringing such issues to the attention of the public health commissioner or state governor.

Other potentially productive partnership activities were suggested. State and local partnerships might include community coalitions to identify barriers to screening and treatment among unscreened or rarely screened populations; information collected could be used to improve access and the cultural sensitivity of all cervical cancer services. These coalitions also could mobilize local leadership from a variety of local institutions (e.g., academic, medical, community-based organizations, the faith community, educators, commerce, and the general public) toward the common goal of reducing cervical cancer mortality. In addition to the existing HRSA primary care centers in public housing projects, partnership with the Department of Housing and Urban Development (HUD) was suggested as a way of reaching women who live in

subsidized housing units. Partnerships with community-based agencies working with specific populations (e.g., foreign-born women) in which trust relationships already are established can provide a crucial bridge to bring women into established screening programs. The Cancer Control Collaborative includes educational sessions designed to inform providers and administrators about screening and followup for certain cancers. The program promotes local partnerships to improve the comprehensiveness and quality of care and to provide a forum for disseminating information about program successes and challenges.

3. Strengthening Advocacy for Cervical Cancer

Currently, advocacy for cervical cancer is limited, in part because of its association with sexual behavior and the small number of cases relative to certain other cancers (e.g., lung, colorectal, breast). It was suggested that NCI identify a core group of cervical cancer survivors who could spearhead advocacy for the disease, communicate to decision-makers a sense of urgency about the disease (e.g., cervical cancer is preventable and no American woman should ever die from it), and work to dispel the stigma associated with cervical cancer as a sexually transmitted disease. In fact, a number of advocacy groups with an interest in cervical cancer already exist: examples include the National Cervical Cancer Coalition, the Intercultural Cancer Council, and the National Council of La Raza Institute for Hispanic Health.⁷⁹ Such organizations could form the nucleus of a collaborative and coordinated national advocacy effort.

Local or regional advocacy networks could be formed in high mortality areas. These advocates could identify state and tribal leaders with an interest in cervical cancer to explore the possibility of regional and tribal coalitions to address cervical cancer mortality, as described above. To help develop a cadre of effective advocates, a national funding source might be established to support cervical cancer advocacy activities and training at the local level and to develop tool kits for use by local advocacy organizations.

Issues identified by the CCMP as ripe for advocate intervention included: (1) insurance coverage issues, such as proposing legislation to fund treatment of all uninsured and underinsured women diagnosed with cervical cancer, not limited to the NBCCEDP and Treatment Act; (2) ensuring that cervical cancer is addressed in existing and developing state cancer control plans; and (3) advocating for cancer control plans in states where they do not yet exist.

Research Needs

Clearly, our understanding of the natural history of cervical cancer in underserved areas of the U.S. remains incomplete. Information is lacking on the characteristics of at-risk women (and their families) and the health care environments in geographic areas with high cervical cancer mortality. More detailed geographic information is needed. Targeted studies and data samples are needed to study the effects of SES, race, and culture on health and disease outcomes in specific populations and environments. In

addition, a better understanding of local populations is required to ascertain the influence on cervical cancer mortality of insurance status, transportation, lack of medical infrastructure, HPV prevalence, smoking, sexual practices, condom use, micronutrients, social and mental health support, and other factors. This information is needed to ascertain the effect of risk-factor reduction on incidence, morbidity, and mortality. Similarly, without adequate data it is difficult to determine with certainty what infrastructure exists or is needed to help alleviate the problem (e.g., number and type of health care professionals, transportation systems). Finally, detailed data systems, especially in the poorest parts of the U.S. such as Appalachia and the Deep South, are needed to evaluate the success of programs and interventions.

The Common Scientific Outline (<http://researchportfolio.cancer.gov/cso.html>) adopted by NCI, DOD, ACS, and other public and private research funding agencies offers the ability to reduce redundancy in research activities and identify research gaps.

Recognizing these areas of need, the CCMP participants identified six (6) key research emphases:

1. Community-Based Research

The importance of finding local solutions to local problems was a recurrent theme throughout the CCMP discussions, and the need for community-based and community-involved research was emphasized. Addressing this need will require enhancements to community-oriented research infrastructure.

The NCI-supported Special Populations Networks and its follow-on, the Community Networks, represent one effort to meet this need. In addition, research training is needed to facilitate community members' participation in research design and implementation. Cervical cancer survivors also can provide valuable insight into research project and intervention design. The process of Community-Based Participatory Research (CBPR) is well described by the Agency for Healthcare Research and Quality (AHRQ) at the Web site: <http://www.ahrq.gov/research/cbprrole.htm>.

2. HPV Testing and Vaccine Research

Several areas of need in HPV-related research were enumerated. Those related to screening included:

- Determining the optimal frequency and role of HPV testing (i.e., as a Pap test followup or primary screen).
- Determining the relationship and patterns, if any, of HPV prevalence by age in high mortality areas.
- Assessing the impact of telling people they have evidence of HPV infection.

Screening tests for HPV, which have shown excellent sensitivity for detecting precancerous cervical intraepithelial neoplasia (CIN) II and III lesions, are available and are accepted by insurers for reimbursement, usually after a Pap test finding of ASCUS (atypical squamous cells of undetermined significance). The combined HPV/DNA test is now accepted for reimbursement by health plans covering approximately

150 million women.⁸⁰ The combined test also is covered by Medicare as a follow-up test and by the NBCCEDP and some state Medicaid programs as a primary screening tool.⁸¹

Continued research to develop more affordable and effective HPV tests will almost certainly continue. The feasibility of HPV self-screening should be further explored. Analyses of the cost effectiveness of routine HPV testing should proceed as this may prove to be more cost effective than the usual two repeat Pap tests now recommended following an abnormal Pap test. For many health agencies, getting women to return for the two additional tests can be the most expensive aspect of screening. These cost-benefit analyses will need to be conducted.

As noted, a preventive vaccine against HPV-16 has been tested in a double-blind trial and found to be effective in preventing infection and CIN. NCI recently initiated a Phase 3 HPV-16 prevention trial in Costa Rica. Routine HPV vaccination may still be a decade away and may not fully address the problem of undetected long-term HPV infection in women older than age 45. Developing one or more effective and affordable HPV preventive vaccines is crucial to cervical cancer control. In addition, it will be essential to conduct the research needed to determine the vaccines' acceptability to at-risk populations (particularly for use in adolescents prior to the onset of sexual activity) and to develop and disseminate the communication and health services interventions that will be required to ensure that the vaccine reaches those who need it. Acceptability studies, it was emphasized, should

be completed well in advance of the vaccine's availability, so that when the vaccine is ready, the mechanisms to deploy it rapidly and effectively will be in place. Similarly, research will be needed for any treatment vaccine that may be developed in the future. The NCI Gynecologic Cancers Progress Review Group (PRG)⁸² identified the development of HPV prophylactic and therapeutic vaccines as a priority for the cervical cancer research agenda because effective vaccines would reduce dramatically the incidence of HPV infection and HPV-related neoplasia and also significantly reduce the cost of screening for cervical cancer. The PRG also underscored the need for government and industry partnership and collaboration to speed the development of HPV vaccines.

3. Improved Screening Technologies and Screening Interventions

CCMP participants suggested that additional research still is needed to develop better, but still affordable, screening tests for cervical abnormalities, to assess the sensitivity and specificity of liquid cytology (e.g., Thin-Prep™) Pap tests, and to assess the feasibility of novel screening and treatment strategies for hard-to-reach populations. It was anticipated, however, that better HPV testing could supplant the need for improved Pap tests.

4. Other Social/Behavioral, Health Services, and Intervention Research

Experience to date relative to diverse health conditions demonstrates that multicomponent interventions are usually the most effective.

Because of the heterogeneity of populations within racial/ethnic groups and within regions with high cervical cancer mortality, more detailed data is needed to better understand and characterize subpopulations at the regional, state, and local levels to help in determining how best to reach them and motivate lasting behavior change. This may include finding ways to establish infrastructure to provide services, link services, provide transportation, disseminate information, and train and pay nonphysicians to provide some services which, in urban areas, are provided by physicians or specialists. In addition, studies of the impact of cultural factors on education and on screening and treatment decision-making are needed.

Greater NCI and ACS support for applied behavioral and social research on women's attitudes and knowledge is needed to inform development of culturally sensitive interventions to increase screening participation. Ethnographic studies have the potential to collect textured data with better relevance than simple epidemiologic data. Analysis is needed based on socioeconomic status and other social issues to elucidate the effects of social position and economic level on cervical cancer mortality in identified populations. Further, it was suggested that studies be conducted to better understand the resilience and other characteristics that help target-population women withstand harsh social and environmental conditions. It may be possible to build upon these factors to improve access and utilization and to reduce disparities.

To date, little research has been done to justify the implementation of many interventions

or to measure their effectiveness. Community case studies on specific issues should be conducted before deciding which interventions to implement. A rapid review of the existing literature on lay health advisors was suggested as were studies to collect further evidence on the efficacy and cost effectiveness of lay health advisors and patient navigators. NCI and CDC were urged to fund pilot studies of successes from one program or geographic area in other locations to identify interventions that are effective across regions. Moreover, successes in outreach to hard-to-reach populations concerning other diseases (e.g., heart disease, diabetes) should be evaluated to determine how these successes could be applied to cervical cancer outreach and other interventions. AHRQ, through its Primary Care Practice-Based Networks and Center for Outcome and Effectiveness Studies, can be of assistance in carrying out or partnering with NCI or other Federal agencies to conduct such studies.

Little information is available, either nationally or related to specific populations (particularly in areas where there is little or no choice of treatment provider), on cervical cancer treatment patterns and patient management, including treatment of recurrences and end-of-life care. These areas require further study.

5. Follow-Back Studies

Follow-back studies typically examine patient records, conduct interviews (if possible), and evaluate the health system experience and disease outcomes of the patient. Such studies are invaluable for understanding failures of cervical

cancer screening, diagnosis, and treatment, but also are instructive regarding health care system gaps overall. A limited number of such studies have been conducted relative to cervical cancer; these suggest that most cervical cancer cases occur in women who have never been screened or whose last test was three or more years prior to diagnosis. Among recently screened women, new cases often have been found to result from false-negative screening results,^{83,84,85} while among women with positive screening tests, cases more often resulted from incomplete diagnostic evaluation.^{86,87,88} Women with lower SES, no insurance, or other financial barriers, and older women are more likely to have less timely or incomplete followup of abnormalities.⁸⁹

CCMP participants maintained that additional follow-back studies are needed that focus on women with advanced cervical cancer in high mortality regions or those who have died from the disease. The objective should be to determine where and why lapses in patient screening, education, treatment, supportive services, and followup are occurring. These studies will inform the development of tailored interventions to address identified gaps across the continuum of care. The studies should include comparison groups, and risk factors should be defined. Studies either should be conducted regionally, or results should be reported by region.

6. Data Collection and Surveillance

Participants suggested that NCI and CDC jointly fund rapid case ascertainment of cervical cancer cases using SEER and NPCR registries targeting high mortality geographic areas and populations.

Multidisciplinary teams and community representatives would then be needed to design effective survey tools to help identify barriers to services experienced by target-group women. In addition, it was felt that collecting patient narratives is important to illuminate the qualitative aspects of cases, combining moving personal stories with compelling data presentations to motivate action by policy-makers, funders, advocates, other community stakeholders, and target populations.

Other suggested data enhancements and refinements included:

- Adding standard data elements to cancer registries on precancerous lesions, cervical pathology, and hospital discharges.
- Improving data on treatment patterns, including treatment of recurrences and palliative care.
- Developing uniform data sets for patient navigation.
- Establishing uniform data sets on SES, education, and Pap test history.
- Conducting data analyses by SES in addition to, or instead of, race/ethnicity.
- Enhancing cancer maps to distinguish mortality rates among racial/ethnic groups, specifically separating data for white Hispanic women from white non-Hispanic women.
- Improving data collection at the local level to permit small-area analysis and comparison of the mortality risk of heterogeneous local populations with national data.

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- Making cervical cancer, and perhaps even carcinoma *in situ* or severe dysplasia, reportable diseases.

Conclusions

The Center to Reduce Cancer Health Disparities believes that the nation's public health care system can do a better job of delivering cervical cancer and related health care to women who need these services, and has reached the following five conclusions.

1. Cervical Cancer Mortality Is an Avoidable Cause of Death and a Marker for Conditions That Contribute to Health Disparities

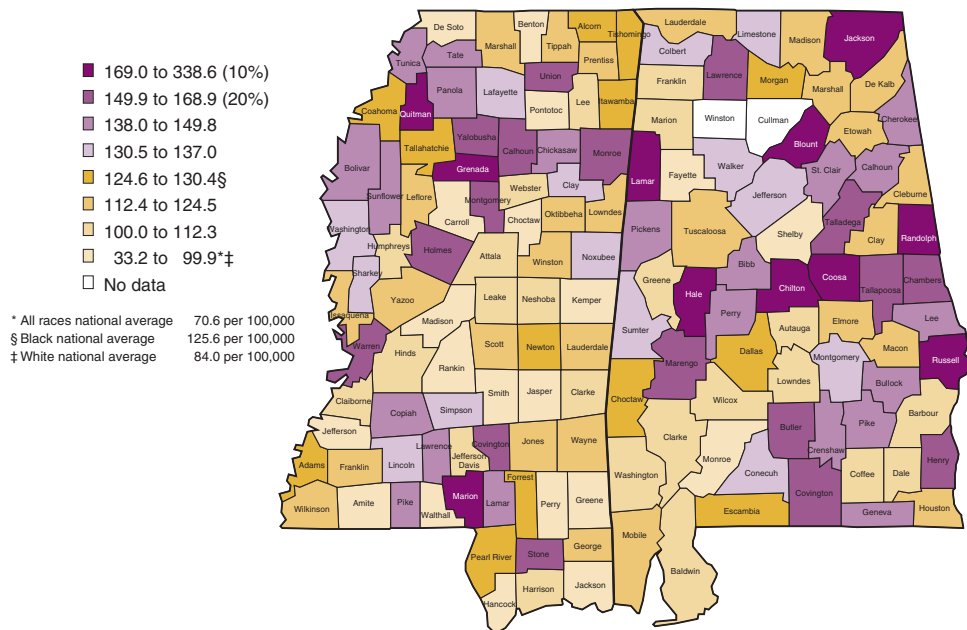
Cervical cancer in America is overwhelmingly a disease of poor women with low educational attainment who are not receiving Pap tests. In the 1990s, U.S. women experienced at least 71 percent higher cervical cancer mortality in high-poverty counties than in low-poverty counties. U.S. cervical cancer mortality increased with increasing area poverty for women in all racial/ethnic groups.⁹⁰ In addition to being an avoidable cause of death, cervical cancer mortality is a marker for the ill health and human suffering of women who are uninsured, underinsured, and/or depend on publicly funded health services. These women frequently underutilize screening and other preventive health services, lack a usual source of care, and avoid the health care system or refuse needed care that is not free because they cannot afford it. Cultural incompatibility with available health care providers, language and literacy problems,

childcare barriers, and distrust of government programs and personnel exacerbate difficulties in reaching these populations of women.

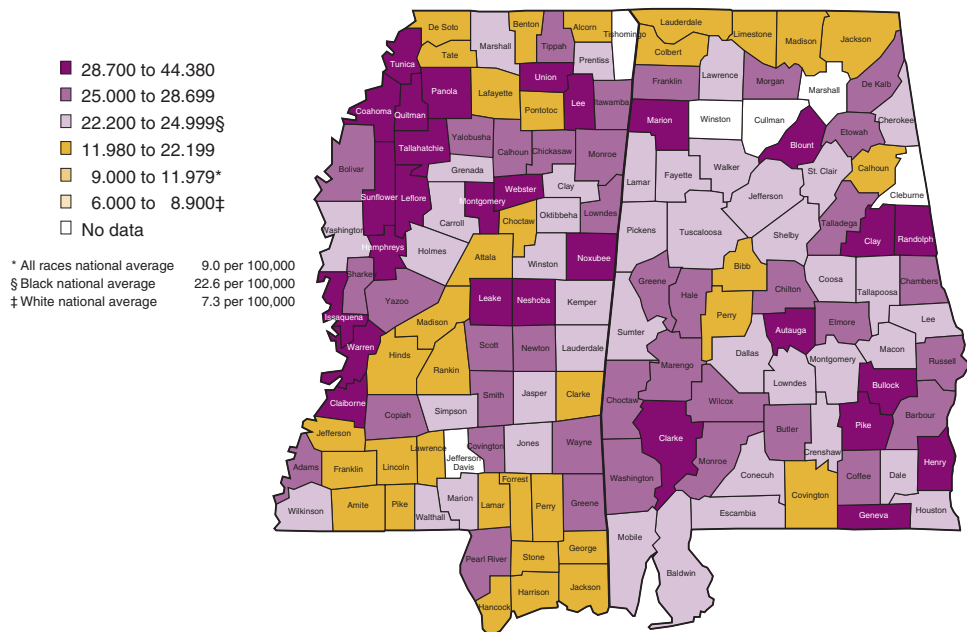
The same populations of women who are experiencing high levels of cervical cancer mortality also are at risk for other screenable and treatable conditions. Data on African American women in the Deep South (Alabama and Mississippi) and white women in parts of Appalachia (West Virginia and Kentucky) illustrate this situation clearly.⁹¹ The women in these high cervical cancer mortality areas also experience excessive mortality from breast cancer (Maps 6 and 10) and colorectal cancer (Maps 5 and 9) as well as heart disease (Maps 7 and 11) and cerebrovascular disease (Maps 12 and 15), and there is high infant mortality (Maps 13 and 16) in these regions as well. In both areas, poverty levels are far above the national average (Maps 14 and 17), and these populations are characterized by lower educational attainment levels, geographic isolation, lack of transportation, greater exposure to environmental and occupational hazards, and poor housing.⁹²

Although comparable data on other diseases was not compiled for other populations with known high cervical cancer mortality rates (Latinas along the Texas-Mexico border, Vietnamese Americans in central California, Alaska Native women, and Native American women in the Northern Plains states), their disease patterns are believed to be substantially similar. Targeted interventions and resources are required to eliminate the cervical cancer mortality disparity in these geographic areas and among these populations.

Map 12. Cerebrovascular Mortality Rate: Black Female, 1969–1999 (Alabama and Mississippi)

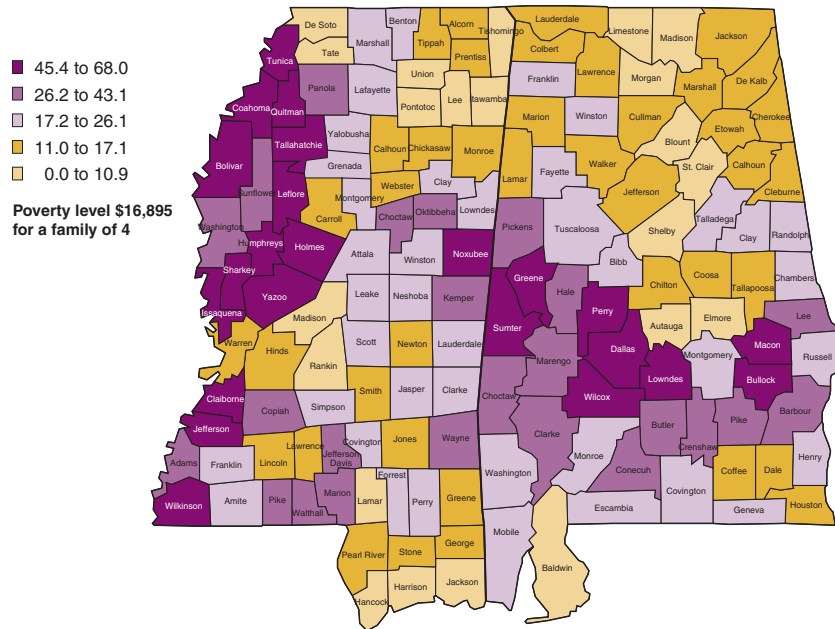


Map 13. Black Infant Mortality Rate, 1969–1999 (per 1,000 Births) (Alabama and Mississippi)



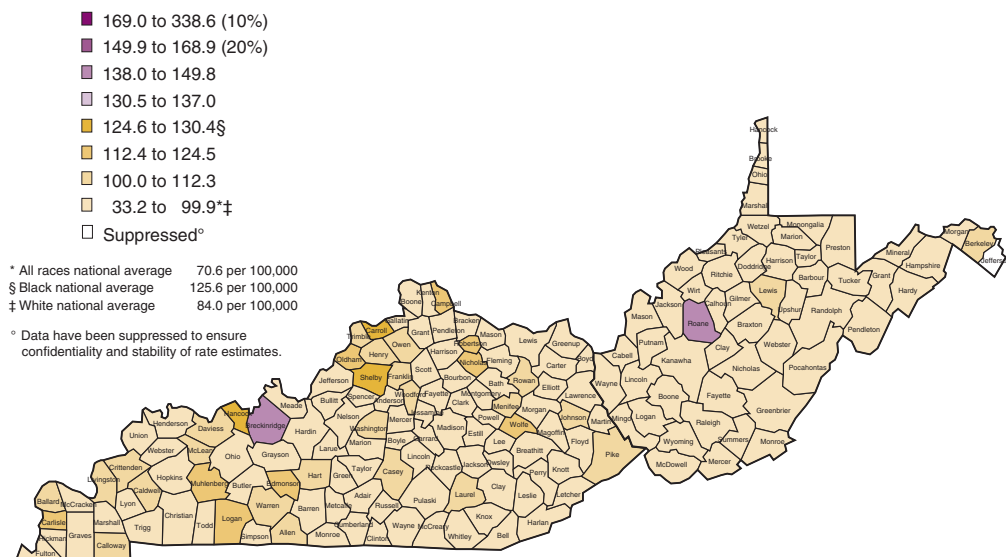
Maps prepared from data provided by: Surveillance, Epidemiology, and End Results (SEER) Program (www.seer.cancer.gov) SEER*Stat Database: Mortality–All COD, Public-Use With County, Total U.S. (1969–1999), National Cancer Institute, DCCPS, Surveillance Research Program. Cancer Statistics Branch. Underlying mortality data.

Map 14. Percent of Persons Below the Poverty Level in 1999 (Alabama and Mississippi)



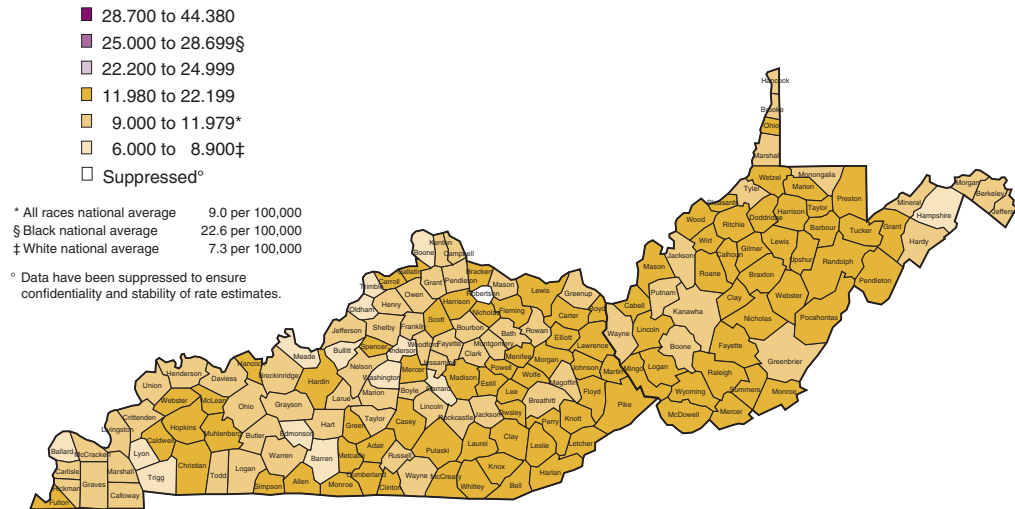
Prepared by County Census 2000 with American Fact Finder.

Map 15. Cerebrovascular Mortality Rate: White Female, 1969–1999 (Kentucky and West Virginia)



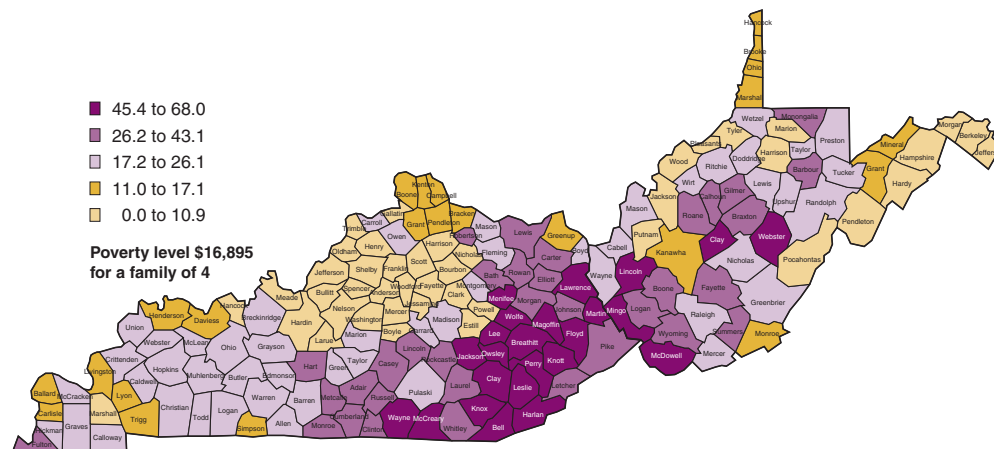
Map prepared from data provided by: Surveillance, Epidemiology, and End Results (SEER) Program (www.seer.cancer.gov) SEER*Stat Database: Mortality–All COD, Public-Use With County, Total U.S. (1969–1999), National Cancer Institute, DCCPS, Surveillance Research Program. Cancer Statistics Branch. Underlying mortality data.

Map 16. White Infant Mortality Rate, 1969–1999 (per 1,000 Births) (Kentucky and West Virginia)



Map prepared from data provided by: Surveillance, Epidemiology, and End Results (SEER) Program (www.seer.cancer.gov) SEER*Stat Database: Mortality--All COD, Public-Use With County, Total U.S. (1969–1999), National Cancer Institute, DCCPS, Surveillance Research Program. Cancer Statistics Branch. Underlying mortality data.

Map 17. Percent of Persons Below the Poverty Level in 1999 (Kentucky and West Virginia)



Prepared by County Census 2000 with American Fact Finder.

2. Addressing Cervical Cancer Mortality Offers an Important Opportunity to Address the Nation's Growing Concern About Persistent Health Disparities

The Administration has identified both prevention and health disparities as areas needing significant attention and improvement. Increasingly, policy-makers and researchers in the health services and health policy fields recognize the many forces that contribute to health disparities and the reduced use of prevention-oriented health services.⁹³ These include the individual and aggregate effects of underlying negative economic and living conditions, health services infrastructure and organization problems, lack of transportation infrastructure, cultural issues, and education/information deficits.⁹⁴

Focusing on the populations at highest risk for cervical cancer leads us to the locations needing special attention in providing not only cancer-related care but also comprehensive health services to women at risk for numerous treatable health problems. Moreover, effectively addressing cervical cancer mortality can provide a model for action—an opportunity to address not only the health problems facing women with high cervical cancer mortality but also the full set of human circumstances that contribute to health disparities. To make a positive impact on the lives of underserved women, these human conditions must be acknowledged as part of the problem to be addressed in crafting solutions tailored to specific localities and populations. To the maximum extent possible, local leaders and cancer survivors should be part

of planning teams for patient-centered intervention, programs, and research design, and be involved in implementation and evaluation efforts as well.

3. Vulnerable Populations Must Be Provided With Necessary Preventive, Acute Care, and Disease Management Services

With more than 44 million beneficiaries,⁹⁵ Medicaid is a critical part of the safety net for most low-income Americans, and in many states Medicaid costs are one of the largest expenses in the state budget. Despite efforts to slow its growth, Medicaid costs have increased 25 percent in the past two years, and enrollment is growing at the fastest pace in a decade.⁹⁶ At least 29 states have recently proposed or enacted Medicaid program changes to limit eligibility and curtail services.⁹⁷ Cuts also have been proposed in many state-funded public health service and hospital indigent/charity care programs. The Community Health Centers (CHCs) funded by the HHS HRSA and similar safety-net health providers are under severe fiscal pressure due to Medicaid and Medicare reimbursement changes, and they are more challenged than ever to reach and serve their target populations, particularly in rural areas. These providers are struggling to fulfill their mission as they shoulder an increasing burden of uncompensated care without commensurate increases in their Federal funding.

The Center on Budget and Policy Priorities reported that the President's 2006 budget proposes to reduce net Federal funding for

Medicaid by \$45 billion over the next ten years without producing any accompanying state savings. This could result in states reducing Medicaid coverage and benefits and thereby adding to the number of poor Americans without health care coverage.⁹⁸

HRSA centers, however, are currently undergoing a period of program expansion^{99,100} and reorganization designed to improve both the number and location of centers in operation as well as the scope and organization of their services. Communities that have both high insurance coverage and extensive CHC capacity tend to have the best access, although the former appears more important. Funding of insurance coverage expansions is likely to produce greater gains in access than if an equivalent level of funding were invested in CHCs. Policymakers should consider CHC expansions as a complement to insurance coverage expansions rather than as a substitute.¹⁰¹ Thus it is an especially timely juncture for assessing how HRSA and other federally supported programs (e.g., Centers for Disease Control and Prevention Breast and Cervical Cancer Screening, and the HHS Office of Women's Health Centers of Excellence) can together enhance their ability to provide more comprehensive and coordinated "whole woman" programs of care to their target populations and provide the critical link to tertiary services for women with diagnosed or suspected cancer.

In 2003, Congress passed a tax cut measure that includes \$20 billion in relief for state governments, half of which is intended to offset escalating Medicaid costs by temporarily

increasing the Federal matching rate.¹⁰² (The states' use of these funds, however, has not been documented.) Such an infusion of Federal funds for Medicaid will not, however, solve the question of how to provide adequate and compassionate cancer and other health services to those who lack the resources to participate in the private health insurance market. Other strategies for managing Medicaid growth are under consideration at both Federal and state levels. In 2005, the Senate Budget Committee chair proposed a \$14 billion reduction in Medicaid spending over five years.¹⁰³

Ways must be found to assure that vulnerable populations, including the uninsured working poor and others not eligible for Medicaid and/or Medicare, receive necessary preventive care, acute care, and disease management services. Proposals to give states greater latitude in designing their Medicaid programs must include provisions to ensure that the most vulnerable populations in each state—whether characterized by geographic locale, race/ethnicity/immigration status, age, educational attainment, or other characteristics—are not abandoned. Because risk of cervical cancer is so strongly related to other vulnerabilities, existing cervical cancer and other health disparities are quite likely to worsen unless the safety-net goal is ensured.

4. Innovation, Commitment, and Creativity Are Crucial to Finding Ways to Use Available Resources More Efficiently and Effectively

Change can occur if the will exists to make it happen. To create effective patient-centered

health systems, it will be necessary to change from an acute care system orientation to one that emphasizes prevention, including changes in the human circumstances that contribute to health disparities. Current access barriers (insurance, cultural, geographic), fragmentation of care, and outreach and information inadequacies must be eliminated. Necessary enabling services (e.g., translation, transportation, patient navigation) must be added. Optimal interventions have multiple components, but currently resources to deliver such interventions are least available in communities where they are needed most. Innovation and creativity will be needed to make the most of scarce resources both in intervention research and in program design and implementation.

In 2002, DHHS commissioned an Institute of Medicine (IOM) report to identify bold ideas for fostering rapid health system change that would take into account serious systemic problems including escalating costs, quality and safety shortcomings, growing numbers of uninsured people, racial and ethnic disparities in access and quality of care, and workforce shortages.¹⁰⁴ The IOM suggested a range of demonstration projects that could spark such systemic change, including projects involving community health centers, information and communication technology infrastructure improvements, chronic care delivery, and state health insurance strategies. Such proposals should be considered seriously in developing ways to improve care for women who depend on publicly funded health care.

5. Leadership and Partnership Are Needed to Create Change

Another recent IOM report¹⁰⁵ urges the Federal Government, using certain types of Federal health facilities as laboratories of innovation, to provide leadership in health care quality improvement efforts. Though CHCs are not among the facility types specified, it is likely that some lessons learned in other federally supported health facilities (e.g., Indian Health Service primary care centers) may be applicable to CHCs, particularly those in rural areas. The HRSA/NCI/CDC Cancer Collaboratives, which focus specifically on CHCs, should likewise offer lessons that could be used to improve care in other types of federally supported health centers.

DHHS has chosen to use cancer as a model for addressing health disparities and NCI to facilitate, promote, and coordinate partnerships among Federal agencies to address persistent disparities such as the high cervical cancer mortality rates in identified geographic regions and populations. Though NCI provides an impetus for action for creating change in health care systems and improving health care quality, no one agency or organization can effect these changes alone. The importance of collaboration and partnership is critical, not only among Federal agencies, but also among state cancer planners, health departments, and Medicaid agencies; hospitals; other non-Federal providers; medical societies; accreditation organizations; advocates; community education/information and support organizations; local business communities; and academia. The need for

greatly enhanced partnerships and collaboration at all levels and between the public and private sectors to improve public health has been detailed by others.^{106,107,108,109}

Recommendations

The NCI Center to Reduce Cancer Health Disparities recommends specific actions and targeted interventions and resources to eliminate the cervical cancer mortality disparities suffered by women in several geographic regions of the nation. These actions are divided into four key strategy categories: *access* (encompassing services, outreach, and navigation); *information and communication*; *collaborations, partnerships, and advocacy*; and *research*. Each major objective is listed with specific recommendations for reaching the goal. These recommendations are summarized in Table 1 and are closely related to the recommendations of the Trans-HHS Cancer Health Disparities Progress Review Group, *Making Cancer Health Disparities History* (<http://www.chdprg.omhrc.gov>). The relationships are shown in Table 2.

Access—Outreach, Services, Navigation

1. Intensify *outreach to women who have rarely or never been screened* for cervical, breast, or colon cancer and other screenable/treatable diseases.
 - Funding for the CDC Breast and Cervical Cancer Early Detection Program should be increased sufficiently over a 5-year period to enable all eligible women to be screened.
2. Enable women who rely on publicly funded health services to have a “medical home”—*a usual source of health care*.
 - Coordinate existing HRSA-funded Community Health Centers (CHC), Federally Qualified Health Centers (FQHCs), state and county health departments, and private primary care practices to provide a usual source of care for all women’s health issues.
3. Provide *patient navigators* who help women through the health system once an abnormality has been detected. This would help eliminate the *disconnects between primary care, screening services, and followup/treatment*.
 - Increase patient navigator programs established through local hospitals, primary health centers, or other available community resources to help women who have an abnormal Pap test obtain diagnostic, treatment, and supportive services as needed.

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- The DHHS Center for Medicare and Medicaid Services (CMS) should approve meritorious requests from states for Section 1115 waivers and other innovative proposals to support patient navigator services.
 - Expertise in planning and implementing patient navigator programs should be shared through a national conference to facilitate development of new and improved programs.
4. Increase the number of *female providers of the patient's gender/race/ethnicity*.
- A coordinated plan should be developed and implemented to increase the number of female and minority physicians and other providers (including nurses and other health workers trained to perform screening tests and colposcopy) in areas with high cervical cancer mortality. Resources that may be brought to this effort include new or existing public and private scholarship programs, HRSA's National Health Service Corps, and other HRSA resources targeted to provide a diverse, culturally competent health workforce in medically underserved areas.
5. Improve *coverage and reimbursement* for cancer-related services.
- Any uninsured woman with a cervical or other cancer should be presumed eligible for Medicaid or Medicare for the duration of her treatment and prescribed follow-up care. The allowable duration of cancer-specific follow-up care (including coverage of supportive services, treatment of recurrences, and other care) is an issue under discussion at CMS.
6. Improve the quality of care in rural areas through *telemedicine and multidisciplinary consultations*.
- The NCI should solicit proposals to bring telemedicine services for review of diagnostic test results and treatment recommendations to areas with high cervical cancer mortality. CMS currently provides reimbursement for these services.
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- ## Information and Communication
1. Improve *awareness and knowledge* about cervical cancer and cervical cancer mortality through the development and provision of *linguistically and culturally appropriate information*.
- Identify populations both at high risk of death from cervical cancer and having no or limited linguistically or culturally appropriate information about the disease. Working with community members, create materials that are appropriate for the target population.
 - Public and private agencies should collaborate to develop and implement an awareness and education media campaign that would be funded nationally but implemented regionally so that it could be tailored to high-risk populations and geographic areas.

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- Train and support a cadre of lay health workers drawn from communities with high mortality rates. Use *lay health workers* to increase population awareness of cervical cancer and the importance of screening.
2. Improve *provider-patient communication* through provider education and availability of language translation.
 - Develop and distribute tools to providers that will be given to patients to encourage screening, overcome barriers, and stress the importance of followup for abnormal findings.
 - Develop and implement training programs for providers emphasizing the importance of (a) patient screening history and advice, (b) communication with patients on the importance of screening, and (c) culturally competent provider care.
 3. Provide a *central resource detailing “best practices” for cervical and other cancers, including evidence-based interventions.*
 - Create a Web site to list evidence-based interventions and tools that can be downloaded by provider organizations and used in or adapted to varied care settings. This process has begun with development of the Cancer Control PLANET Web site (<http://CancerControlPlanet.cancer.gov>).
 4. Improve *medical records maintenance and retrieval systems through the use of rapidly evolving information technology.*
 - Automated medical records would provide rapid access and review of patients’ medical information and reduce the incidence of repeated or neglected procedures. Develop and disseminate information systems to remind physicians, track patients, and provide physicians feedback on their practice patterns and how to improve them when needed. The goal is to fulfill information requirements cost effectively.
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- ## Research
1. Optimize *human papillomavirus (HPV) testing and HPV vaccine development* to eliminate the primary biologic cause of cervical cancer.
 - Research should continue to develop an effective and affordable HPV vaccine and determine how best to ensure its acceptability.
 2. Improve *screening technologies and screening interventions* to bring affordable screening to all women.
 3. Conduct other *social/behavioral, health services, and intervention research* to better understand high-risk populations and develop interventions to improve their care.

- Identify through *follow-back studies* those health system issues that are contributing to cervical cancer mortality rates in high mortality geographic areas.
 - Identify improved methods of reaching hard-to-reach populations; and provide additional evidence on the benefits and cost effectiveness of community health advisors and patient navigators.
 - All grants for intervention development should be population based and include a scientifically sound evaluation component. Grants also should include funding for the transition of successful interventions to community operation and financial self-sufficiency.
4. Improve *data collection and surveillance* activities related both to quantitative and to qualitative understanding of cervical cancer.
- Federal data collection activities should be expanded to include information on cancer treatment patterns, including barriers to care, treatment of recurrences, and end-of-life care.

Collaborations, Partnerships, and Advocacy

1. Establish and strengthen *partnerships that promote a “whole woman” approach to care.*
 - HHS agencies that administer or finance cancer-related services and other chronic disease care should strengthen existing collaborative arrangements and establish new partnerships at national, regional,

and local levels to create patient-centered, integrated, and coordinated health services that will make it possible for women who rely on publicly funded health services to have a “medical home” that promotes a “whole woman” approach to their care. This would enable all screening to be performed in a single facility or setting.

- Linking primary care clinics to hospital-based diagnostic and treatment services is a crucial part of this goal.
- Policy changes should be enacted that will allow local programs greater flexibility in the use of Federal categorical program funds, thereby improving opportunities for coordination of care and cost efficiency.
- As part of a larger national strategy, supplemental funding from a consortium of Federal agencies should be provided to several community networks to reduce cancer disparities, state health departments, or other established organizations in specific states or regions of states with high cervical cancer mortality. This funding will be used to build in each location a consortium of stakeholders that should include health-related agencies, local educators, labor-related agencies, and employers. The funding will also support coalition planning and implementation of a demonstration project in each location to (a) improve cancer screening and

treatment and (b) better coordinate all care provided to women at publicly funded health facilities. The goals should be to demonstrate both behavioral change and substantially reduced cervical cancer mortality within five years. Lessons learned from such demonstrations should be implemented rapidly in other locations or nationally as appropriate.

2. Develop and implement an agenda to *provide and sustain funding for coalitions, partnerships, and community-based quality health services, education, and prevention programs.*
 - DHHS agencies that administer or finance cervical cancer-related services and other chronic disease care should form a permanent, action-oriented, problem-solving working group to continually examine and improve the coordination, continuity, and effectiveness of outreach, navigation, education/information, and treatment services for women in areas of high cervical cancer mortality. Input should be solicited regularly from state and local health systems and related agencies. The working group should be comprised of officials who are empowered to set agency policy.
 - Strengthen advocacy for cervical cancer, currently in nascent stages.

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Appendix A

Reducing Health Disparities in High Cervical Cancer Mortality Regions—Phase 1

Roundtable Agenda

Holiday Inn Emerald Beach
Corpus Christi, TX
November 28–30, 2001

Wednesday, November 28, 2001

8:00 a.m.–8:15 a.m.	Welcome and Overview <i>Harold Freeman</i>
8:15 a.m.–8:30 a.m.	Update of Surveillance Evidence Review Process <i>Jon Kerner</i>
8:30 a.m.–9:00 a.m.	Review/Update Incidence and Mortality Data <i>Susan Devesa (10 min) and Carol Kosary (10 min) (NCI)</i> <i>Irene Hall (10 min) (CDC)</i>
9:00 a.m.–9:15 a.m.	Literature Review Findings on Incidence and Mortality <i>Jeanne Mandleblatt and Robin Yabroff (Georgetown)</i>
9:15 a.m.–9:45 a.m.	Discussion
10:00 a.m.–10:35 a.m.	Review/Update Stage of Disease at Diagnosis and Screening Data <i>Irene Hall (10 min) (CDC)</i> <i>K. “Vish” Viswanath or Nancy Breen (25 min) (NCI)</i>
10:35 a.m.–10:50 a.m.	Literature Review Findings on Stage of Disease at Diagnosis and Screening <i>Jeanne Mandleblatt and Robin Yabroff (Georgetown)</i>
10:50 a.m.–11:15 a.m.	Discussion

11:15 a.m.–11:45 a.m.	Review/Update Treatment Data <i>Susan DesHarnais (10 min) (ACoS)</i> <i>Robin Yabroff (10 min) (Georgetown)</i> <i>Ted Trimble (10 min) (NCI)</i>
11:45 a.m.–12:00 p.m.	Literature Review Findings on Treatment <i>Jeanne Mandleblatt and Robin Yabrof (Georgetown University)</i>
12:00 p.m.–12:30 p.m.	Discussion <i>Il Given, Michigan State University</i> Topic: Cervical Cancer Treatment Among Women Insured by Medicaid
1:30 p.m.–2:15 p.m.	Overview of Concept Mapping and Review the Map <i>Mary Kane and Dan McLinden</i>
2:15 p.m.–2:45 p.m.	Concept Mapping Group Exercise I (Grouped by Table) <i>Mary Kane and Dan McLinden</i>
3:00 p.m. –3:45 p.m.	Issue Identification—Group Discussion
3:45 p.m.–4:15 p.m.	Global Perspective of Concept Map Ratings <i>Mary Kane and Dan McLinden</i>
4:15 p.m.–5:00 p.m.	Concept Mapping Group Exercise II (Grouped by Table) <i>Mary Kane and Dan McLinden</i>
5:00 p.m.–5:30 p.m.	Opportunities for Action—Group Discussion
6:00 p.m.	Dinner <i>Guest Speakers: Everett Rogers, author of Dissemination of Innovations, and K. “Vish” Viswanath, National Cancer Institute</i> Topic: Dissemination and Diffusion

Thursday, November 29, 2001

8:00 a.m.–8:15 a.m.	Recap of Day 1 and Goals for Day 2 <i>Harold Freeman</i>
8:15 a.m.–9:00 a.m.	Potential Reduction in Incidence and Mortality Simulation <i>Jeanne Mandleblatt and Robin Yabroff (Georgetown University)</i>
9:00 a.m.–9:15 a.m.	Identifying Key Local Information for Action Planning (County Fact Sheets) <i>Steve Wyatt</i>
9:15 a.m.–10:00 a.m.	Making a Measurable Difference: Moving Data into Action <i>Jon Kerner</i>
10:15 a.m.–11:30 a.m.	Breakout Session I—(5 Regional Groups) –Recommend actions that should be taken at the national level (e.g., Congress, HHS, etc.)
11:30 a.m.–12:30 p.m.	Regional Groups Report Back
12:30 p.m.–1:30 p.m.	Lunch <i>Guest Speaker: Maria Fernandez, University of Texas Health Science Center at Houston</i> Topic: The Colonias in Texas
1:30 p.m.–3:00 p.m.	Breakout Session II –Develop one-year action plan of rank-ordered priorities to reduce cervical cancer mortality in high mortality counties in your state
3:15 p.m.–4:00 p.m.	Regional Groups Report Back
4:00 p.m.	Roundtable Meeting Adjourns

Preliminary Think Tank Agenda

(Think Tank Core Members Remain)

Thursday November 29, 2001

- 4:30 p.m.–5:00 p.m. Discussion of Final Report Issues and Solicit Leaders for Drafting Recommendations for Final Report Outline
Joe Harford
- 6:30 p.m.–6:45 p.m. Using Concept Mapping and Surveillance Evidence Review Data for Identifying Key Issues
Jon Kerner
- 6:45 p.m.–8:00 p.m. Identify Key Issues and Leaders/Brainstorming Activity
Mary Kane

Friday November 30, 2001

- 8:00 a.m.–8:30 a.m. Charge to Think Tank Members
Harold Freeman
- 8:30 a.m.–10:00 a.m. Assignment to Groups 1–5
–Break out into 4 or 5 groups to collaborate on recommendations/suggestions for action on first 4–5 key issues identified on Thursday night
- 10:15 a.m.–12:00 p.m. Assignment to groups 6–10
–Break out into 4 or 5 groups to collaborate on recommendations/suggestions for action on the remaining key issues identified on Thursday night
- 12:45 p.m.–1:15 p.m. Results of Brainstorming Activity
Outline of Table of Contents for Report
- 1:15 p.m.–2:00 p.m. Wrap-Up and Adjourn

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Executive Summary—Phase 1

Despite an overall decline in cervical cancer mortality nationally, relatively consistent geographic disparities in mortality have persisted for decades. Because of these longstanding disparities, and because the tools needed to prevent cervical cancer deaths are available, the National Cancer Institute (NCI) Center to Reduce Cancer Health Disparities (CRCHD) launched a project to present the data, literature, stakeholder input, conclusions, and recommendations for policy changes and interventions that will drastically reduce, if not virtually eliminate, disparities in cervical cancer death. This document summarizes outcomes from the first of two phases of this effort.

Phase 1 Activities

Phase 1 focused on collecting and analyzing the historical and most current data on cervical cancer incidence, screening, treatment, and mortality in the United States. NCI staff assembled and reviewed available statistics; these data were presented to the Center and also were shared with NCI staff with an interest in cervical cancer research. In addition, NCI commissioned a review of the literature published between 1966 and May 2001, as well as some studies published between 1950 and 1965, on cervical cancer mortality among rural women.

From November 28–30, 2001, a Roundtable was held in Corpus Christi, TX. The 144 participants included Federal, state, and local planning and program personnel; researchers

from several disciplines with an interest in cervical cancer; clinicians; advocates; educators; communications specialists; and NCI CRCHD planning, and cancer control personnel. Findings from the data and literature reviews were shared with the participants.

Prior to the meeting, attendees were asked to participate in an online “concept mapping” exercise in which they submitted ideas for actions they believed could reduce cervical cancer mortality in their own state or region. These ideas were collated, redundancies were eliminated, and the ideas were sorted into conceptual categories. The condensed data were displayed on a “concept map” that identified related ideas in four major areas:

- outreach and services
- education and communication
- advocacy and partnership
- research

This map was presented to Roundtable attendees, who were asked to use these potential focus areas to consider possible policy changes, activities, or interventions that could be carried out at the Federal level, at the state/local level, and in specific geographic regions with high cervical cancer mortality.

Cross-Cutting Issues and Needs

In addition to a broad range of ideas in the four possible focus areas, several cross-cutting issues

and needs and suggestions for addressing them emerged from the Roundtable discussions:

- Build a *network* of people involved in all areas of cervical cancer education, screening, treatment, and advocacy, using the Roundtable participants as the initial core of this network.
- Provide *proactive support* at the national level; however, action must take place predominantly at the community level to address local problems.
- Provide *technical assistance* to foster collaborations, coordination, and publication by and among states and regions; facilitate ties to existing clinical and research networks and consortia.
- *Improve accountability and quality control*; responsibility for implementing recommendations must be clear and the products of recommendations must be evaluated.
- Ensure that *cultural relevance* permeates all activities in each of the focus areas.
- Develop mechanisms and provide funding needed to ensure the *sustainability of successful interventions*.
- Move toward a “*whole woman*” approach to *women’s health* that integrates cervical cancer outreach, screening, education, and followup into other services, builds on existing infrastructure, and minimizes the fragmentation currently caused by categorical funding.

Next Steps

Phase 2 of the project will tap the understanding derived from the data, literature, and Roundtable input to develop better insight into people’s daily life experiences that contribute to cervical cancer mortality disparities—most specifically, poverty, other adverse circumstances, or cultural and/or linguistic differences. CRCHD will convene one or more additional meetings to expand upon the findings from the Roundtable and related activities.

Final Report Plan

CRCHD’s cervical cancer mortality project will conclude with a report containing recommendations for action including, but not limited to, the four major focus areas. The report will be presented to the Director, NCI, and will be made available to decision-makers at national, regional, state, and local levels. CRCHD will be proactive in informing policy-makers and partners about opportunities for policy change and intervention. NCI follow-up activities will be based on the conclusions and recommendations contained in the final report and subsequent discussion about them with stakeholders in the cervical cancer community.

A copy of the full report can be obtained from:

NCI Center to Reduce Cancer Health Disparities
6116 Executive Blvd., Suite 602
Rockville, MD 20892

Appendix B

Regions With High Cervical Cancer Mortality—Phase 2

Think Tank Agenda

National Cancer Institute
Center to Reduce Cancer Health Disparities
Bethesda, Maryland
May 8, 2002

9:00 a.m.–9:30 a.m.	Opening Remarks and Introductions <i>Harold Freeman</i>
9:30 a.m.–9:45 a.m.	Process Employed in Phase 1 of the Project <i>Jon Kerner</i>
9:45 a.m.–10:00 a.m.	Phase 1 Findings <i>Harold Freeman</i>
10:00 a.m.–10:15 a.m.	Updated and New Cervical Cancer Mortality Maps <i>Susan Devesa</i>
10:15 a.m.–10:30 a.m.	Questions/Discussion <i>Group</i>
10:45 a.m.–12:15 p.m.	Discussion <i>Group</i> Question 1: What are the characteristics of each population and its culture that may be contributing to higher cervical cancer mortality? <ul style="list-style-type: none">• Hispanics along the Texas-Mexico border• African Americans in the Rural South• Whites in Appalachia

1:15 p.m.–2:45 p.m.

Discussion

Group

Question 2: What aspects of the conditions in which the population lives may be contributing to higher cervical cancer mortality?

- Hispanics along the Texas-Mexico border
- African Americans in the Rural South
- Whites in Appalachia

3:00 p.m.–4:15 p.m.

Discussion: To Where From Here?

Group

Question 3: Based on what we know, what can/should be done now to save lives?

Question 4: What else must we do/learn?

- Commission in-depth case studies?
- Document best practices/potentially replicable successes?
- Conduct infrastructure analyses?

4:15 p.m.–4:30 p.m.

Final Thoughts

Group

4:30 p.m.

Adjourn

Question 1: Factors to consider:

Overall world view
Religious affiliations and views
View of disease and health
Concept of prevention
Social and family support systems/importance of extended family
Family relationships/male-female power relationships
Importance of privacy/willingness to disclose personal information
Sexual attitudes and taboos
Educational attainment/literacy/health literacy
Ways of seeking information
Culture of poverty/primacy of basic needs
Other?

Question 2: Factors to consider:

Discrimination/social injustice
Political structure and environment
Places of residence/geographic isolation
Housing
Transportation available: personal, public
Communication channels and technology (telephone, television, radio, Internet, word of mouth)
Job types and availability of work
Income
Exposure to environmental and workplace hazards
Health care resources in the area, including information
Access to health care resources, including insurance, or ability to pay
Childcare issues
Other?

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Appendix C

Cervical Cancer Mortality— A Marker for the Health of Poor and Underserved Women: Toward an Interagency Collaboration To Reduce Disparities

Think Tank Agenda

National Cancer Institute
Center to Reduce Cancer Health Disparities
Bethesda, Maryland
October 28–29, 2002

October 28, 2002

8:30 a.m.–8:45 a.m.	Welcome, Introductions, and Overview <i>Harold Freeman</i>
8:45 a.m.–9:00 a.m.	Project Activities to Date <i>Harold Freeman</i>
9:00 a.m.–9:15 a.m.	Presentation of Maps <i>Barbara Wingrove</i>
9:15 a.m.–9:30 a.m.	Discussion
9:45 a.m.–10:15 a.m.	Cervical Cancer and Other Health Conditions in Appalachia <i>Gene Lengerich</i> <i>Angel Rubio</i> <i>Pamela Brown</i>
10:15 a.m.–10:30 a.m.	Discussion
10:30 a.m.–11:00 a.m.	Cervical Cancer and Other Health Conditions in the Deep South <i>Ed Partridge</i>
11:00 a.m.–11:15 a.m.	Discussion

12:15 p.m.–1:15 p.m.	<p>Presentations by Agency Representatives:</p> <ul style="list-style-type: none"> • Centers for Medicare and Medicaid Services (CMS) <i>David Greenberg</i> • Health Resources and Services Administration (HRSA) <i>David Stevens</i> • National Cancer Institute (NCI) HRSA collaboration <i>Neeraj Arora</i>
1:15 p.m.–1:35 p.m.	Discussion
1:35 p.m.–2:35 p.m.	<p>Agency Presentations, continued</p> <ul style="list-style-type: none"> • Department of Health and Human Services (DHHS) Office of Minority Health (OMH) <i>Nate Stinson</i> • Agency for Healthcare Research and Quality (AHRQ) <i>Kay Felix-Aaron</i>
2:35 p.m.–2:55 p.m.	Discussion
3:10 p.m.–4:15 p.m.	<p>Agency Presentations, continued</p> <ul style="list-style-type: none"> • Centers for Disease Control and Prevention (CDC) Chronic Disease Center <i>Nancy Lee</i>
4:15 p.m.–4:35 p.m.	Discussion
4:35 p.m.–4:45 p.m.	Wrap-Up, Day 1

October 29, 2002

8:30 a.m.–8:45 a.m.

Brief Recap, Overview of Day 2
Harold Freeman

8:45 a.m.–3:30 p.m.

Discussions on the following questions:

8:45 a.m.–9:45 a.m.

Question 1: What do you see as the major barriers, bottlenecks, gaps, or disconnects in the *total system* of federally supported health care programs serving poor and underserved women?

9:45 a.m.–10:45 a.m.

Question 2: How do you believe publicly funded health services for women experiencing cervical cancer and other health disparities could be better coordinated or otherwise improved?

11:00 a.m.–12:00 p.m.

Question 3: Assuming no additional funding becomes available, what could each agency do to better coordinate services or otherwise extend its reach to the target populations? Is it possible to redirect existing funds to achieve greater synergies, or to share or piggyback resources?

1:00 p.m.–2:15 p.m.

Question 4: How can this group of agency representatives and the CRCHD continue to work together to realize improvements in the health of women who depend on publicly funded health services? Are there other agencies or resources that should be involved?

2:15 p.m.–2:30 p.m.

Wrap-Up and Adjourn

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