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The preliminary results from the Appalachia Leadership Initiative on Cancer suggest that capacity, defined as a greater degree of interconnectedness between entities as they coordinate efforts for planned action, has been enhanced in the Appalachian cancer control system. Process evaluation activities will assess whether initial anticipated outcomes such as coalition leadership, coalition stability, coalition activities and resource acquisition will lead to intermediate outcomes such as an increase in community awareness, reduced barriers to cancer control services, increase in screening services, and a more favorable state at diagnosis in breast and cervical cancer for the women of Appalachia.

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Despite decreasing U.S. cancer mortality rates, progress toward meeting the Healthy People 2010 Goals for Cancer is being hampered by the nation's inability to deal effectively with the greater cancer burden being borne by certain vulnerable populations. These "special populations," defined as population groups at a higher-than-average risk of death, disease, and disability, include people with low incomes, older Americans, African Americans, Hispanics, Native Americans, and other ethnic populations. In recognition of the cancer risk among African Americans and Hispanics, the National Cancer Institute (NCI) took steps over the last two decades to improve cancer detection, treatment, and survival rates in these populations by establishing the National Black Leadership Initiative on Cancer (NBLIC) in 1986 and the National Hispanic Leadership Initiative on Cancer (NHLIC) in 1991. Both of these initiatives were developed to address the barriers to cancer prevention and control associated with race and ethnicity. At the same time, it was recognized that the relatively high rate of poverty in these populations was perhaps the most important barrier to their participation in cancer control activities.¹⁻³

The NCI has stated that it also considers rural residents to constitute a "special population."⁴ Rural Americans tend to be older, poorer, less educated, and more likely to be uninsured than their urban/suburban counterparts.⁵ Rural communities have higher rates of chronic illness and disability and report poorer overall health status than their urban counterparts. Residents of rural areas generally have less contact and fewer visits with physicians and, in general, lower levels of preventive care.⁶ In addition to factors related to rural health status and practices, there are systemic factors related to rural

life in general, for example, lack of public transportation and lower levels of other community services, that may also contribute to less-than-optimal cancer control. All of these risk factors are particularly evident in the largely rural and predominantly white population of Appalachia.

Overview of the region

Appalachia, as defined by the Appalachian Regional Commission, includes 399 counties in 13 states.⁷ According to the 1990 census, 20.7 million people, 8 percent of the U.S. population, live in Appalachia. Approximately 92 percent of the population is white, 1 percent Native American, and 7 percent African American. Of the 399 counties, 266 (67 percent) are categorized as rural, and a majority of these counties have been designated by the federal government as health professional shortage areas. In many of these counties, a significant segment of the population is poor, less educated, older, and less healthy than the national average. The level of literacy, roughly indicated by the grade of formal schooling completed, is generally lower in Appalachia than in most of the rest of the country.⁷

These socioeconomic problems are reflected in a variety of health care indices, including higher overall mortality, higher mortality from heart disease and cancer, and higher infant mortality, as shown in Table 1. Although Appalachia's 1950-to-1980 breast cancer mortality rates are comparable to the U.S. rate,⁸ it is one of the areas where, as a whole, breast cancer mortality has increased at a faster pace than in the rest of the United States.

Excessive mortality from cervical cancer was noted in several central Appalachian counties between 1970 and 1980. In Appalachian Kentucky, the 1987 incidence of invasive cervical cancer for white women in those counties with the highest cervical cancer mortality was approximately twice the rate for white women nationally, as reported by the NCI Surveillance, Epidemiology and End Results Program (SEER), and about the same as the SEER rate for African American women.⁹

Overview of the project

CHARACTERISTIC	TOTAL UNITED STATES	TOTAL APPALACHIA	RURAL APPALACHIA
Demographic and socioeconomic			
Census population, 1990	248,790,500	20,714,400	6,488,400
Per capita income, 1990	\$12,736	\$15,358	\$13,877
Percentage unemployed, 1990	8.8	6.2	7.8
Percentage below poverty, 1990	22.8	18.8	28.7
Percentage of population with a high school diploma, 1990	75.1	68.4	60.0
Health status			
All causes mortality, 1988	871.7	1,006.2	1,024.9
Heart disease mortality, 1988	394.9	388.9	386.2
Infrequent compliance records, 1986	191.6	239.8	217.4
Population per primary care physician, 1990	156.4	480.8	1,194.6

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TABLE 1

In recognition of the higher burden of disease for some cancers in Appalachia, the NCI issued a request in March of 1992 for applications for cooperative agreements from organizations in the region "to participate in establishing a strong cancer control outreach program in Appalachia." ⁴ Thus the Appalachia Leadership Initiative on Cancer (ALIC) project was created. In the long term, this project was intended to "achieve reductions in cancer incidence and mortality, increases in cancer survival, and increases in the diagnosis of cancers at earlier stages within the Appalachian region." The goals in this research effort were to be achieved by community lay and professional leaders developing and supporting cancer control coalitions that would "design and implement long range, comprehensive, multidisciplinary, and community-wide cancer control outreach projects and stimulate greater cancer control data collection and research efforts."⁴

In September of 1992, the NCI made awards to four research universities to conduct projects covering the Appalachian counties in 11 of the 13 Appalachian states. In two universities, the research was conducted through cancer centers, and in the other two it was conducted through the Cooperative Extension Service (CES). Awardees focused their initial attention on those areas most in need of reducing the barriers to effective cancer prevention and control activities, that is, rural, medically underserved communities. In its focus on the underserved, ALIC resembled the NBLIC and the NHLIC. However, ALIC differed from the other NCI special population initiatives because its priority population was defined by geography rather than by racial or ethnic characteristics.

Northern Appalachia Leadership Initiative on Cancer

The Northern Appalachia Leadership Initiative on Cancer (NALIC), which serves the Appalachian counties of New York, Pennsylvania, and Maryland, was coordinated through the CES, in the College of Agricultural Sciences at Pennsylvania State University, which served as lead agency. In primary partnership with Cooperative Extension in New York and Maryland, the University of Pittsburgh Cancer Institute, and the [American Cancer Society](#) (ACS) in the three states, [Pennsylvania State University](#) staff proposed a cancer control project to reach limited-resource residents through interorganizational collaboration at local, regional, and state levels.

The NALIC project strategy was to involve the county-based staff of both Cooperative Extension and the ACS and to extend that relationship to numerous local organizations and individuals willing to mobilize their communities to reach the underserved. Through the efforts of key coalition initiators, identified by the CES and ACS, 13 NALIC coalitions were created in 15 counties, 11 in Pennsylvania and 2 in New York. Over time, each coalition recruited local residents, lay leaders, professionals, and members of organizations that reflected the unique characteristics of its locale. Nearly 180 organizations are now represented on the coalitions. They include the Grange, American Association for Retired Persons, the Head Start program, food pantries, literacy councils, libraries, churches, offices on aging, local health departments, family planning councils, hospitals, and health centers. Civic leaders, students, retirees, survivors, teachers, nurses, doctors, and many other individuals are also involved.

Leadership development and community participation strategies were incorporated into the NALIC project design through extensive technical assistance. NALIC field staff and project-affiliated partners provided skills training and support on the topics of community health assessment, coalition building, cancer resource management, strategic planning and evaluation, development of low literacy materials, media and marketing, grant writing, and storytelling.

At state and regional levels, collaborative efforts were developed to enhance local coalition activities. NALIC project staff promoted formal affiliate partnerships between the coalitions and Regions 3 and 4 of the NCI's Cancer Information Service (CIS), Pennsylvania and New York Departments of Health, [Pennsylvania State University's](#) Institute for the Study of Adult Literacy, and several other university and state agencies.

North Central Appalachia Leadership Initiative on Cancer

The North Central Appalachia Leadership Initiative on Cancer (NCALIC) was based at the Mary Babb Randolph Cancer Center (MBRCC) within the Robert C. Byrd Health Sciences Center at [West Virginia University](#). NCALIC covered West Virginia, the only state entirely within the Appalachian region, and southeastern Ohio through a primary partnership between MBRCC, the lead agency, and the Cancer Services of Grant/Riverside Methodist Hospitals.

NCALIC had seven coalitions in West Virginia and four coalitions in southeastern Ohio. NCALIC chose intervention counties based on established public health districts as well as the presence of adequate community interest and health-related services and resources to conduct effective interventions in otherwise poor, rural, medically underserved areas of the two states.

At the state level, the NCALIC affiliated partners were the Region 10 CIS serving West Virginia, Virginia, and Ohio; the West Virginia and Ohio Breast and Cervical Cancer Early Detection Programs (BCCEDP) of the Centers for Disease Control and Prevention; and the West Virginia and Ohio Divisions of the ACS. The CIS has provided initial staff training, outreach planning assistance, access to culturally appropriate materials, and the most current scientific information on breast and cervical cancer. The BCCEDP has offered community coalition leadership, intervention planning, education for coalition members on breast and cervical cancer, and access to screening providers. The ACS has aided in coalition leadership, recruitment of members, volunteer training, and support for survivors. NCALIC has in this way developed effective coalitions capable of assessing their counties' cancer control needs and designing and implementing cancer control programs and activities that appeal to the values and culture of their community.

Central Highlands Appalachia Leadership Initiative on Cancer

The Central Highlands Appalachia Leadership Initiative on Cancer (CHALIC), with headquarters at the Lucille Parker Markey Cancer Center at the [University of Kentucky](#), was working in the Appalachian counties of Kentucky, Tennessee, and Virginia. Its primary partners were the Center for Rural Health at the [University of Kentucky](#), East Tennessee State University, and Virginia Polytechnic Institute and State University.

CHALIC's Healthy Homeplace Leadership Training Program, led by 25 core trainers, provided 27 coalitions or county action teams with the skills to assess their local needs and resources with regard to cancer control issues and encouraged members to set goals and gather data to design a cancer control plan. Unlike the other regional projects, in which ALIC staff was directly involved in stimulating the development of local coalitions, the CHALIC approach utilized Healthy Homeplace trainees to stimulate coalition development.

Trainers worked in teams of three to present core materials and guide the county-level trainees through four one-day sessions conducted over a nine-month period. Training sessions were interspersed with community action assignments in which the county teams solicited the participation of other community members and groups in conducting community inventories, developing strategic plans, implementing action priorities, and evaluating the success of their efforts. At the local level, representatives of a broad spectrum of organizations, including health professionals, consumers, and advocacy groups, were mobilized to participate in the coalitions, with the initial trainees serving as trainers of the new coalition members.

Southern Appalachia Leadership Initiative on Cancer

The CES of North Carolina State University served as the lead agency for the Southern Appalachia Leadership Initiative on Cancer (SALIC), which was active in 11 counties in the Appalachian areas of North Carolina, South Carolina, and Georgia. SALIC consortium members (primary partners) were [North Carolina State University](#), [Clemson University](#), University of Georgia Cooperative Extension Services, [University of South Carolina](#), and Greenville Hospital System, South Carolina. Affiliate partners included the Region 6 NO CIS for Carolina and Georgia based at [Duke University](#), the Centers for Disease Control and Prevention BCCEDP in each state, the ACS, and Project ASSIST.

Clusters of four counties in North Carolina, three in South Carolina, and four in Georgia were randomly selected for study. A state project coordinator in each state mobilized professionals from health and health-related agencies, community leaders, and community volunteers to form county cancer control coalitions to focus on breast and cervical cancer screening. The emphasis was on reaching rural women. Coalition members were trained in coalition building and maintenance and in strategic planning. The CIS for the Carolinas and Georgia provided intensive cancer control training for the SALIC state coordinators, who, in turn, supported by CIS staff and assisted by local health professionals, trained county coalition members and community groups. The CIS continues to provide ongoing training and technical assistance. Educational materials were furnished by both the CIS and ACS.

County coalitions also fostered the formation of community action teams as a means of increasing awareness and broadening the dissemination of cancer control materials and messages. With support from the county coalitions, these community groups provide cancer-related information and refer family, friends, and neighbors to local breast and cervical cancer screening programs.

Goals of the project

The goals shared by all four ALIC projects were to reduce breast and cervical cancer morbidity and mortality, increase breast and cervical cancer survivorship, and increase earlier stage cancer diagnoses of breast and cervix within Appalachia through community-based cancer control coalitions. An additional goal of ALIC was to enhance local capacity and competence in cancer control by fostering the development of community coalitions to pursue cancer control objectives; by designing and implementing long-range, comprehensive, multidisciplinary, and community-wide cancer control outreach projects; and by stimulating greater cancer control data collection and research efforts."

Thus, all four projects, regardless of their unique individual characteristics, attempted to answer the question, "How effective are community cancer coalitions as an intervention strategy for social and organizational change in achieving cancer control objectives?" The hypothesis being tested was, "The development of community coalitions throughout Appalachia will result in an increase in early-stage diagnosis of breast and cervical cancer with a concomitant decrease in late-stage diagnosis of these diseases, an increase in cancer survivorship, and a decrease in breast and cervical cancer mortality over time."

Because the outcomes being sought were long term in nature, a series of process indicators was developed to address the following intermediate hypotheses:

Hypothesis 1: preliminary project-level ALIC interventions will result in the development of regional cancer control partnerships;

Hypothesis 2: county-level ALIC interventions will result in the development of community cancer coalitions across Appalachia;

Hypothesis 3: ALIC coalitions will develop local cancer control activities targeting breast and cervical cancer; and Hypothesis 4: counties in which ALIC coalitions are active will have an increase in screening for breast and cervical cancer.

The assumption was that as ALIC coalitions worked to increase cancer control activities, decrease barriers to accessing cancer control services, and increase sustainable local response mechanisms to other cancer control problems, the incidence of cancer morbidity and mortality would decrease. Using county profiles that included socioeconomic, demographic, epidemiological, and/or social indicators, control and intervention counties in the 10 states were selected in which these hypotheses were tested.

Method

The overall evaluation research strategy was to treat an four projects as a single nonrandomized community trial. Although each project had developed its own individual coalition development strategy at the time of response to the request for application (RFA), these strategies were modified during the joint planning phase to provide the level of cross-project consistency needed for programwide evaluation. The four projects agreed that ALIC's evaluation plan should include qualitative and quantitative measures of process and outcome. Because measurement of the long-term goal of reducing death from breast and cervical cancer obviously extended beyond the life of this program, ALIC included a variety of indicators of individual and community behavior change in the evaluation plan to serve as proxy measures of long-term change.

Process evaluation. Reflecting the hypotheses and the use of community-based coalitions as a cancer control intervention, the process evaluation was divided into three major phases: partnership development (Hypothesis 1), county coalition development (Hypothesis 2), and coalition activities (Hypotheses 3 and 4). Because the four projects varied somewhat in their strategies and approaches to partnership and coalition development, a major challenge was to design a data collection system that could be used to capture programwide, project-specific, and coalition-specific process data. A process evaluation subcommittee that included representatives from all projects, as well as NCI-supported consultants and technical staff, designed a database that became known as the ALIC Process Evaluation Data System (PEDS).

PEDS is a custom application of the Microsoft ACCESS database management system that includes the major items needed to track the various aspects of coalition development and coalition activities at both the project and coalition levels. It contains project-level data for each of the four projects, including information about primary and affiliated partners (roles, training, and technical assistance provided), existing cancer control programs in the region, and environmental factors influencing the project, and it contains county-coalition-level data, including individual initiators and members (as well as the organizations they represent and the role or roles they play in the coalition), degree of formal organization of the coalition (officers, bylaws, etc.), presence of a formal community assessment and implementation plan, number of meetings per six-month period, number of training sessions for members, type and degree of technical assistance received, and cancer control activities performed (type, target audience, outcome). These data items have been organized into six semiannual time periods beginning in July 1994 and ending in June 1997.

The various data elements contained in PEDS can be linked to intermediate programwide or cross-project results—the focus of this paper—as well as to long-range outcome measures to assess the effectiveness and efficiency of various types of project- and/or coalition-specific strategies in reducing cancer mortality. Screening resources and activities were selected as the early process evaluation indicators of community behavior related to the likelihood of achieving long-term reduction in deaths from breast and cervical cancer.

Outcome evaluation. As indicated earlier, project outcomes will be measured over time. Behavioral indicators used as early outcome measures will include changes in the rate of mammography screening among women over 65 years, using Medicare data, and changes in the rate of both mammogram screening and Papanicolaou (Pap) smear screening among medically underserved women, using data from the Behavioral Risk Factor Surveillance System. Intermediate outcome measures will be changes in the rate of early-stage diagnosis for breast and cervical cancer using data from state cancer registries. Evaluation of long-term outcomes extending beyond the time frame of NCI funding will include changes and trends in mortality rates for breast and cervical cancer.

Linking process and outcome. As outcome measures become available, the process and outcome components of the evaluation design will be linked for a comprehensive ALIC-wide program evaluation. Specific data contained in PEDS will be linked with data for the various outcome measures. Program evaluation will compare outcomes with coalition- and activity-specific variables and with measures of effectiveness and efficiency for the identified time periods.

RESULTS

Results reported in this paper will focus on preliminary analysis of partnership development, coalition development, and coalition activities (see Table 2).

Partnership development (Hypothesis 1). Before results were visible in the county and community coalitions, many partnerships had to be established and strengthened among "communities of interest" in the dozen universities from which the ALIC program coinvestigators were recruited, from the major partners involved in each project (ACS, CIS, CES, the National Breast and Cervical Cancer Early Detection Program, etc.), and from the major providers of cancer prevention and control services (state health departments, hospitals, primary care clinicians, etc.). A total of 139 primary and affiliated partners have stayed active in ALIC for one year or more.

TABLE 2
OVERALL PROFILE OF THE FOUR APPALACHIA LEADERSHIP INITIATIVES ON CANCER PROGRAMS

	ALIC	FOCAL	CHALE	SALE
Local agencies	10	10	10	10
Primary providers	10	10	10	10
Additional providers	10	10	10	10
Number of members	10	10	10	10

(Note: The table content is significantly obscured and partially illegible in the image. The above represents the visible structure and some data points.)

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TABLE 2

Coalition development (Hypothesis 2). A total of 63 county coalitions were developed during ALIC's implementation phase, as shown in Table 2. Collectively, the coalitions had 1,662 active members. In addition, each coalition reached out and involved many hundreds of other community participants in its activities.

Coalition activities (Hypothesis 3). The 63 coalitions working in 71 intervention counties conducted over a thousand activities. As of the last reporting period (January 1997 to June 1997), these activities included 111 breast and cervical screening programs, 35 screening programs for other cancers, 61 health fairs (sponsored by or participated in), 103 media activities, 47 grant proposals written, and 27 programs targeted specifically at health professionals, approximately 500 presentations and outreach activities to increase cancer awareness, and approximately 300 presentations and activities to promote coalition activities.

The baseline data for preintervention screening activities were not consistently available across all Appalachian counties in the study region. Thus, testing Hypothesis 4 was problematic. Investigators are currently attempting to retrieve screening rates for the study region from other secondary sources.

Discussion

The complexity of macro-intervention programs, such as ALIC, that are attempting to achieve behavior change in both individuals and local health care systems presents inherent difficulties for program evaluation.^{13,14} The challenge for evaluators is to hypothesize causal relationships within a model purposely constructed with a myriad of confounding variables.

Yet, the nature of the cancer control problems we currently face requires just such a holistic approach. Only an ecological model that deals with community programs and activities as well as comprehensive, integrated systems approaches and strategies can address these pervasive social problems. As Couto explains, "Disease prevention requires social change. Social change requires participation and commitment of those for whom the change is intended."¹³ It is for this reason that ALIC has adapted a modified community development approach in this research effort.

As Bracht and Kingsbury explain, a community development or community organization model utilizes "a planned process to activate a community to use its own social structures and any available resources (internal or external) to accomplish community goals, decided primarily by community representatives and consistent with local values."¹⁴

Community activation. NCI is one of several organizations in the public and private sectors that during the last decade has employed a mobilization or activation strategy intended to disseminate capacity-generating models throughout the existing cancer control system. The main goal of such a strategy is to ensure the development of a cancer control system that is comprehensive and integrated, both in structure and processes, so as to produce the translation of cancer prevention and control science and concomitant data-driven interventions into effective community practice.

Projects such as COMMIT, ASSIST, Planned Approach to Community Health, Community Chronic Disease Prevention Program, Community Health Promotion Grant Program (Kaiser), NBLIC, NHLIC, and others have been developing the basic knowledge base for these macro-level interventions. Some of these agencies are currently releasing their final evaluation results from these projects.¹⁵⁻¹⁷ The common pattern that emerges across all of these efforts maybe described as an

iterative social change process for enhancing the capacity and competence of the existing chronic disease control system (see Figure 1).

As represented in Figure 1, ALIC began with NCI as the primary change agent initiating a series of organizational and community capacity-building changes to be fostered by research universities. The study purpose was to see if the additional capacity brought to a subsystem outside of the traditional public health infrastructure would assist in meeting the year 2010 goals for cancer and improve the health of the region.



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FIGURE 1

As also shown in Figure 1, each successive phase in the process in Figure 1 was initiated by a specific change agent, successively NC, the four research universities, the regional partnerships, and the county coalitions. The awards from NCI to each of the four universities impacted the existing program and organization at each institution to build capacity within that university's "community" of coinvestigators, subcontracting institutions, and key partners to foster cancer control development by altering the norms, structures, and social relationships within those segments of the university involved in the project. With its enhanced capacity, that particular university "community" is enabled to take active steps toward specific cancer control objectives and to serve, in turn, as a change agent to foster the development of regional cancer control partnerships.

Primary and affiliate partners in each project constitute the ALIC regional partnerships. As noted, these often included the CES, ACS, departments of public health, social service agencies, churches, regional CIS offices, and other universities. These organizations plus their existing cancer control programs (if any) made up the regional partnership "community" referred to in Figure 1. With input from the initial university change agent-including the provision of varying levels of technical assistance and resources-the regional partnership expands its cancer control capability (see Figure 1). With this enhanced capability, the regional partnership can assume the role of change agent and help initiate cancer control activities at the county level.

This regional change agent responsibility is carried out by the paid staff and/or volunteers of the several organizations making up the regional partnership. These individuals, singly or in small groups, work with local organizations and individuals to form one or more coalitions at the county level. The initial county cancer control capacity will vary from one area to another depending on the level of previous cancer control activities in that county, on the evident need for such activities, on the part of the "system" in which changes maybe needed, and on the interest of local citizens. It would be hoped that the successful interaction of the regional change agents) with local citizens would lead to a change in the community cancer control capacity and, in turn, to a meaningful change in both individual and community cancer control behavior.

Thus, throughout all these repetitive processes to "strengthen the social fabric" by creating more supportive norms, more supportive structures, and more supportive social relationships, as shown in Figure 1, the capacity of the cancer control system has been enhanced. It is also at the county coalition level that the majority of PEDS variables are able to provide the most accurate description of the ALIC history during its final implementation phase.

In addition to the iterative process that ALIC has employed, another aspect that makes ALIC different from previous national efforts in community organization such as those previously mentioned was the methodology utilized to track the activation of the "communities" at the national, regional, state, and community levels. The relational design of the PEDS database permits analysis at any of these levels in an individual or combined fashion.

Conclusion

The preliminary results from ALIC suggest that capacity, defined as a greater degree of interconnectedness between entities as they coordinate efforts for planned action, has been enhanced in the Appalachian cancer control system. Future papers will explore in more detail the process and outcome evaluations. Process evaluation activities will assess whether initial anticipated outcomes such as coalition leadership, coalition stability, coalition activities, community adoption, and resource acquisition will lead to intermediate outcomes such as an increase in community awareness, reduced barriers to cancer

control services, increase in screening services, and, most important, a more favorable stage at diagnosis in breast and cervical cancer for the women of Appalachia.

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